

WEBVTT

NOTE duration:"01:07:56"

NOTE recognizability:0.916

NOTE language:en-us

NOTE Confidence: 0.968295035

00:00:00.000 --> 00:00:02.780 Good evening and welcome.

NOTE Confidence: 0.968295035

00:00:02.780 --> 00:00:04.652 My name is Mark Mercurio on the director

NOTE Confidence: 0.968295035

00:00:04.652 --> 00:00:06.672 of the Program for Biomedical Ethics at

NOTE Confidence: 0.968295035

00:00:06.672 --> 00:00:08.835 the Yale School of Medicine and also

NOTE Confidence: 0.968295035

00:00:08.835 --> 00:00:10.365 the Yale Pediatric Ethics program.

NOTE Confidence: 0.968295035

00:00:10.370 --> 00:00:12.080 How is it the young New

NOTE Confidence: 0.968295035

00:00:12.080 --> 00:00:12.935 Haven Children's Hospital?

NOTE Confidence: 0.968295035

00:00:12.940 --> 00:00:16.132 And we get these two groups together

NOTE Confidence: 0.968295035

00:00:16.132 --> 00:00:18.673 and together we we sponsor ethics

NOTE Confidence: 0.968295035

00:00:18.673 --> 00:00:20.237 evening ethics seminars about

NOTE Confidence: 0.968295035

00:00:20.237 --> 00:00:22.433 twice a month and this evening.

NOTE Confidence: 0.968295035

00:00:22.433 --> 00:00:24.820 I'm particularly happy that we have doctor

NOTE Confidence: 0.968295035

00:00:24.879 --> 00:00:27.035 Amy Caruso Brown as our guest speaker.

NOTE Confidence: 0.968295035

00:00:27.040 --> 00:00:29.182 Doctor Amy Caruso Brown is the interim  
NOTE Confidence: 0.968295035

00:00:29.182 --> 00:00:30.970 chair of Bioethics and Humanities,  
NOTE Confidence: 0.968295035

00:00:30.970 --> 00:00:32.574 an associate professor of  
NOTE Confidence: 0.968295035

00:00:32.574 --> 00:00:33.777 bioethics and humanities,  
NOTE Confidence: 0.968295035

00:00:33.780 --> 00:00:36.210 and of Pediatrics at the State  
NOTE Confidence: 0.968295035

00:00:36.210 --> 00:00:38.520 University of New York Upstate.  
NOTE Confidence: 0.968295035

00:00:38.520 --> 00:00:40.446 She is a graduate of the  
NOTE Confidence: 0.968295035

00:00:40.446 --> 00:00:41.409 University of Virginia.  
NOTE Confidence: 0.968295035

00:00:41.410 --> 00:00:43.120 She has an MD from Emory.  
NOTE Confidence: 0.968295035

00:00:43.120 --> 00:00:44.740 She has masters degrees from the  
NOTE Confidence: 0.968295035

00:00:44.740 --> 00:00:46.152 University of Oxford as well  
NOTE Confidence: 0.968295035

00:00:46.152 --> 00:00:47.557 as the University of Colorado.  
NOTE Confidence: 0.968295035

00:00:47.560 --> 00:00:49.350 She completed her residency in  
NOTE Confidence: 0.968295035

00:00:49.350 --> 00:00:51.140 general Pediatrics at the Children's  
NOTE Confidence: 0.968295035

00:00:51.196 --> 00:00:52.851 Hospital of Philadelphia as well  
NOTE Confidence: 0.968295035

00:00:52.851 --> 00:00:54.506 as the University of Colorado

NOTE Confidence: 0.968295035

00:00:54.564 --> 00:00:56.016 Fellowship training in hematology

NOTE Confidence: 0.968295035

00:00:56.016 --> 00:00:57.831 and oncology at Colorado and

NOTE Confidence: 0.968295035

00:00:57.831 --> 00:01:00.248 she's board certified in general,

NOTE Confidence: 0.968295035

00:01:00.248 --> 00:01:02.296 Pediatrics and pediatric imunok.

NOTE Confidence: 0.968295035

00:01:02.300 --> 00:01:04.925 She's also a certified in

NOTE Confidence: 0.968295035

00:01:04.925 --> 00:01:06.500 healthcare ethics consultation.

NOTE Confidence: 0.968295035

00:01:06.500 --> 00:01:08.912 Hope she is has many hats

NOTE Confidence: 0.968295035

00:01:08.912 --> 00:01:10.520 that she wears upstate,

NOTE Confidence: 0.968295035

00:01:10.520 --> 00:01:12.375 but among them she is the thread

NOTE Confidence: 0.968295035

00:01:12.375 --> 00:01:14.209 leader for the ethics and

NOTE Confidence: 0.968295035

00:01:14.209 --> 00:01:16.254 professionalism in the undergraduate

NOTE Confidence: 0.968295035

00:01:16.254 --> 00:01:17.808 medical education program.

NOTE Confidence: 0.968295035

00:01:17.810 --> 00:01:19.290 Her current research interests

NOTE Confidence: 0.968295035

00:01:19.290 --> 00:01:21.510 include impact of social media on

NOTE Confidence: 0.968295035

00:01:21.570 --> 00:01:23.418 trust and communication between

NOTE Confidence: 0.968295035

00:01:23.418 --> 00:01:24.804 physicians and families,  
NOTE Confidence: 0.968295035

00:01:24.810 --> 00:01:25.682 and social,  
NOTE Confidence: 0.968295035

00:01:25.682 --> 00:01:27.862 cultural and legal dimensions of  
NOTE Confidence: 0.968295035

00:01:27.862 --> 00:01:29.170 disagreements between families  
NOTE Confidence: 0.968295035

00:01:29.232 --> 00:01:30.920 and clinicians in Pediatrics.  
NOTE Confidence: 0.968295035

00:01:30.920 --> 00:01:32.586 In the context of her teaching efforts,  
NOTE Confidence: 0.968295035

00:01:32.590 --> 00:01:33.962 she is particularly interested  
NOTE Confidence: 0.968295035

00:01:33.962 --> 00:01:36.020 in the question of how medical  
NOTE Confidence: 0.968295035

00:01:36.086 --> 00:01:37.618 students understand and enact  
NOTE Confidence: 0.968295035

00:01:37.618 --> 00:01:39.150 social responsibility as part  
NOTE Confidence: 0.968295035

00:01:39.150 --> 00:01:41.178 of their evolving professional  
NOTE Confidence: 0.968295035

00:01:41.178 --> 00:01:43.805 identities across societies and  
NOTE Confidence: 0.968295035

00:01:43.805 --> 00:01:45.830 across healthcare systems.  
NOTE Confidence: 0.968295035

00:01:45.830 --> 00:01:48.357 She's a member of the Ethics consultation  
NOTE Confidence: 0.968295035

00:01:48.357 --> 00:01:51.008 service as well as an attending at  
NOTE Confidence: 0.968295035

00:01:51.008 --> 00:01:53.748 Golisano Children's Hospital in Syracuse.

NOTE Confidence: 0.968295035

00:01:53.750 --> 00:01:56.636 We're delighted that doctor Amy Crusoe

NOTE Confidence: 0.968295035

00:01:56.636 --> 00:02:00.387 Brown has agreed to join us today she is,

NOTE Confidence: 0.968295035

00:02:00.390 --> 00:02:01.704 I think, many of you know

NOTE Confidence: 0.968295035

00:02:01.704 --> 00:02:03.069 you've read some of her work.

NOTE Confidence: 0.968295035

00:02:03.070 --> 00:02:05.326 You have read about her as I have,

NOTE Confidence: 0.968295035

00:02:05.330 --> 00:02:06.751 but tonight we get a chance to

NOTE Confidence: 0.968295035

00:02:06.751 --> 00:02:08.219 meet her and to hear from her.

NOTE Confidence: 0.968295035

00:02:08.220 --> 00:02:10.244 So I'm going to ask Amy to speak

NOTE Confidence: 0.968295035

00:02:10.244 --> 00:02:11.957 for a close to an hour.

NOTE Confidence: 0.968295035

00:02:11.960 --> 00:02:13.605 She'll speak to us in 45 minutes

NOTE Confidence: 0.968295035

00:02:13.605 --> 00:02:15.458 in an hour and then afterwards.

NOTE Confidence: 0.968295035

00:02:15.460 --> 00:02:17.932 Am I invite you to submit your questions

NOTE Confidence: 0.968295035

00:02:17.932 --> 00:02:20.290 through the Q&A site and I will.

NOTE Confidence: 0.968295035

00:02:20.290 --> 00:02:23.020 I'll moderate a discussion with Doctor Brown.

NOTE Confidence: 0.968295035

00:02:23.020 --> 00:02:24.388 I'm through the Q&A.

NOTE Confidence: 0.968295035

00:02:24.388 --> 00:02:26.900 We will then have a hard stop.  
NOTE Confidence: 0.968295035

00:02:26.900 --> 00:02:27.916 As always at 6:30.  
NOTE Confidence: 0.968295035

00:02:27.916 --> 00:02:28.678 So as always,  
NOTE Confidence: 0.968295035

00:02:28.680 --> 00:02:30.619 I'll apologize in advance to the person  
NOTE Confidence: 0.968295035

00:02:30.619 --> 00:02:32.432 who has that really good question  
NOTE Confidence: 0.968295035

00:02:32.432 --> 00:02:35.260 at 6:29 that I couldn't get to.  
NOTE Confidence: 0.968295035

00:02:35.260 --> 00:02:38.324 But to respect your time and everyone's time,  
NOTE Confidence: 0.968295035

00:02:38.330 --> 00:02:41.126 we will stop at 6:30 sharp.  
NOTE Confidence: 0.968295035

00:02:41.130 --> 00:02:43.559 In the meantime, there is CME available.  
NOTE Confidence: 0.968295035

00:02:43.560 --> 00:02:45.846 I would remind you and that.  
NOTE Confidence: 0.968295035

00:02:45.850 --> 00:02:47.770 In the chat you can see how to get that.  
NOTE Confidence: 0.968295035

00:02:47.770 --> 00:02:50.626 Then you have to text the text  
NOTE Confidence: 0.968295035

00:02:50.626 --> 00:02:52.760 information for getting CME credit.  
NOTE Confidence: 0.968295035

00:02:52.760 --> 00:02:54.962 And also on our website biomedical  
NOTE Confidence: 0.968295035

00:02:54.962 --> 00:02:57.355 ethics at yale.edu you can see the  
NOTE Confidence: 0.968295035

00:02:57.355 --> 00:02:59.010 schedule for upcoming programs were

NOTE Confidence: 0.874569541428571  
00:02:59.065 --> 00:03:00.470 very happy about the programs  
NOTE Confidence: 0.874569541428571  
00:03:00.470 --> 00:03:02.210 we have lined up this year.  
NOTE Confidence: 0.874569541428571  
00:03:02.210 --> 00:03:04.154 In some ways it's been easier to get  
NOTE Confidence: 0.874569541428571  
00:03:04.154 --> 00:03:06.055 really a stellar speakers like Doctor  
NOTE Confidence: 0.874569541428571  
00:03:06.055 --> 00:03:08.417 Brown because it's easier for them because  
NOTE Confidence: 0.874569541428571  
00:03:08.417 --> 00:03:10.529 we don't have to ask them to travel.  
NOTE Confidence: 0.874569541428571  
00:03:10.530 --> 00:03:13.652 So we try and make lemonade out of  
NOTE Confidence: 0.874569541428571  
00:03:13.652 --> 00:03:15.640 lemons here and and take the zoom  
NOTE Confidence: 0.874569541428571  
00:03:15.698 --> 00:03:17.763 era and use the opportunity to bring  
NOTE Confidence: 0.874569541428571  
00:03:17.763 --> 00:03:19.639 in some really wonderful folks.  
NOTE Confidence: 0.874569541428571  
00:03:19.640 --> 00:03:21.686 And Speaking of really wonderful folks,  
NOTE Confidence: 0.874569541428571  
00:03:21.690 --> 00:03:23.286 I would introduce to you now.  
NOTE Confidence: 0.874569541428571  
00:03:23.290 --> 00:03:24.955 Doctor Amy Caruso Brown and  
NOTE Confidence: 0.874569541428571  
00:03:24.955 --> 00:03:26.620 say Amy it's all yours.  
NOTE Confidence: 0.940811875714286  
00:03:28.330 --> 00:03:30.325 You so much for that wonderful introduction.  
NOTE Confidence: 0.940811875714286

00:03:30.330 --> 00:03:31.280 I'm I'm really excited to  
NOTE Confidence: 0.940811875714286

00:03:31.280 --> 00:03:32.670 be here to talk to everyone.  
NOTE Confidence: 0.940811875714286

00:03:32.670 --> 00:03:35.781 I wish it was in person, but we will  
NOTE Confidence: 0.940811875714286

00:03:35.781 --> 00:03:38.066 have a great conversation nonetheless.  
NOTE Confidence: 0.940811875714286

00:03:38.070 --> 00:03:40.454 Uhm, I had never had any financial or  
NOTE Confidence: 0.940811875714286

00:03:40.454 --> 00:03:42.840 conflicts of interest to disclose. I do.  
NOTE Confidence: 0.940811875714286

00:03:42.840 --> 00:03:44.485 I really like to start with talking  
NOTE Confidence: 0.940811875714286

00:03:44.485 --> 00:03:45.814 about positionality and particularly  
NOTE Confidence: 0.940811875714286

00:03:45.814 --> 00:03:47.884 in the context of social media.  
NOTE Confidence: 0.940811875714286

00:03:47.890 --> 00:03:49.230 I think it's important that  
NOTE Confidence: 0.940811875714286

00:03:49.230 --> 00:03:50.860 people know where I'm coming from.  
NOTE Confidence: 0.940811875714286

00:03:50.860 --> 00:03:53.924 So I came to my work in bioethics  
NOTE Confidence: 0.940811875714286

00:03:53.924 --> 00:03:55.790 through medical anthropology,  
NOTE Confidence: 0.940811875714286

00:03:55.790 --> 00:03:57.698 and you will see some of  
NOTE Confidence: 0.940811875714286

00:03:57.698 --> 00:03:58.334 those anthropological.  
NOTE Confidence: 0.940811875714286

00:03:58.340 --> 00:03:59.960 Influences show up as you talk.

NOTE Confidence: 0.940811875714286  
00:03:59.960 --> 00:04:01.528 As I talk you will certainly see  
NOTE Confidence: 0.940811875714286  
00:04:01.528 --> 00:04:03.036 that I am a pediatric oncologist  
NOTE Confidence: 0.940811875714286  
00:04:03.036 --> 00:04:05.176 and that shows up in how I frame  
NOTE Confidence: 0.940811875714286  
00:04:05.176 --> 00:04:06.712 some of these questions and I'll  
NOTE Confidence: 0.940811875714286  
00:04:06.712 --> 00:04:08.482 try to be really transparent about  
NOTE Confidence: 0.940811875714286  
00:04:08.482 --> 00:04:10.820 where the data I'm talking about is  
NOTE Confidence: 0.940811875714286  
00:04:10.884 --> 00:04:12.669 specific to the oncology setting  
NOTE Confidence: 0.940811875714286  
00:04:12.670 --> 00:04:15.410 and where it's more generalizable.  
NOTE Confidence: 0.940811875714286  
00:04:15.410 --> 00:04:17.902 I also have always had a computer  
NOTE Confidence: 0.940811875714286  
00:04:17.902 --> 00:04:19.943 had Internet since I was about  
NOTE Confidence: 0.940811875714286  
00:04:19.943 --> 00:04:22.050 9:00 and I have had social media  
NOTE Confidence: 0.940811875714286  
00:04:22.122 --> 00:04:24.037 accounts since my early 20s,  
NOTE Confidence: 0.940811875714286  
00:04:24.040 --> 00:04:25.480 and I think that's really important,  
NOTE Confidence: 0.940811875714286  
00:04:25.480 --> 00:04:27.153 so I have not grown up with  
NOTE Confidence: 0.940811875714286  
00:04:27.153 --> 00:04:28.489 this in the way that.  
NOTE Confidence: 0.940811875714286

00:04:28.490 --> 00:04:30.240 Say my Med students have,  
NOTE Confidence: 0.940811875714286

00:04:30.240 --> 00:04:32.784 but I may be more comfortable with social  
NOTE Confidence: 0.940811875714286

00:04:32.784 --> 00:04:35.445 media than some of you or less comfortable,  
NOTE Confidence: 0.940811875714286

00:04:35.450 --> 00:04:38.048 and I've had really some really  
NOTE Confidence: 0.940811875714286

00:04:38.048 --> 00:04:39.347 positive experiences interacting  
NOTE Confidence: 0.940811875714286

00:04:39.347 --> 00:04:41.667 with families on social media and  
NOTE Confidence: 0.940811875714286

00:04:41.667 --> 00:04:43.930 being invited to follow their blogs.  
NOTE Confidence: 0.940811875714286

00:04:43.930 --> 00:04:45.004 I'm also really,  
NOTE Confidence: 0.940811875714286

00:04:45.004 --> 00:04:46.794 deeply suspicious of most of  
NOTE Confidence: 0.940811875714286

00:04:46.794 --> 00:04:48.600 the social media platforms,  
NOTE Confidence: 0.940811875714286

00:04:48.600 --> 00:04:49.140 including Facebook,  
NOTE Confidence: 0.940811875714286

00:04:49.140 --> 00:04:51.030 and I'm sure many of you have  
NOTE Confidence: 0.940811875714286

00:04:51.030 --> 00:04:52.198 seen that in the news,  
NOTE Confidence: 0.940811875714286

00:04:52.200 --> 00:04:55.000 so I try as as a good qualitative  
NOTE Confidence: 0.940811875714286

00:04:55.000 --> 00:04:57.098 researcher should to be aware of  
NOTE Confidence: 0.940811875714286

00:04:57.098 --> 00:04:59.078 that and acknowledge all of that.

NOTE Confidence: 0.940811875714286  
00:04:59.080 --> 00:05:00.776 And I want to present it to you  
NOTE Confidence: 0.940811875714286  
00:05:00.776 --> 00:05:02.577 before I start talking about my  
NOTE Confidence: 0.940811875714286  
00:05:02.577 --> 00:05:04.626 research and how I think social media  
NOTE Confidence: 0.940811875714286  
00:05:04.626 --> 00:05:06.204 is tremendously important to our  
NOTE Confidence: 0.940811875714286  
00:05:06.204 --> 00:05:08.089 communication with families and families,  
NOTE Confidence: 0.940811875714286  
00:05:08.090 --> 00:05:11.570 and particularly the disagreements.  
NOTE Confidence: 0.940811875714286  
00:05:11.570 --> 00:05:13.190 So I wrote traditional objectives,  
NOTE Confidence: 0.940811875714286  
00:05:13.190 --> 00:05:15.614 but I much prefer the idea of guiding  
NOTE Confidence: 0.940811875714286  
00:05:15.614 --> 00:05:17.677 questions for a talk like this and  
NOTE Confidence: 0.940811875714286  
00:05:17.677 --> 00:05:19.718 the questions I'm going to try to  
NOTE Confidence: 0.940811875714286  
00:05:19.718 --> 00:05:22.046 answer or at least explore with you today.  
NOTE Confidence: 0.940811875714286  
00:05:22.050 --> 00:05:24.162 Our first what makes social media  
NOTE Confidence: 0.940811875714286  
00:05:24.162 --> 00:05:26.104 different from older ways of  
NOTE Confidence: 0.940811875714286  
00:05:26.104 --> 00:05:27.968 interacting and information seeking?  
NOTE Confidence: 0.940811875714286  
00:05:27.970 --> 00:05:30.082 What are the ethical issues that  
NOTE Confidence: 0.940811875714286

00:05:30.082 --> 00:05:31.936 arise at the intersections of  
NOTE Confidence: 0.940811875714286

00:05:31.936 --> 00:05:33.826 social media and Children's Health?  
NOTE Confidence: 0.940811875714286

00:05:33.830 --> 00:05:35.446 How my or really?  
NOTE Confidence: 0.940811875714286

00:05:35.446 --> 00:05:37.466 How does social media catalyze  
NOTE Confidence: 0.940811875714286

00:05:37.466 --> 00:05:39.199 conflicts and disagreements?  
NOTE Confidence: 0.940811875714286

00:05:39.200 --> 00:05:41.927 And then how can we all of us pediatricians?  
NOTE Confidence: 0.940811875714286

00:05:41.930 --> 00:05:43.010 Ethicists, parents,  
NOTE Confidence: 0.940811875714286

00:05:43.010 --> 00:05:43.550 mentors,  
NOTE Confidence: 0.940811875714286

00:05:43.550 --> 00:05:44.630 other stakeholders.  
NOTE Confidence: 0.940811875714286

00:05:44.630 --> 00:05:47.619 How can we respond productively to those  
NOTE Confidence: 0.940811875714286

00:05:47.619 --> 00:05:50.737 agreements in the context of social media?  
NOTE Confidence: 0.940811875714286

00:05:50.740 --> 00:05:53.926 So I do think that social media is distinct,  
NOTE Confidence: 0.940811875714286

00:05:53.930 --> 00:05:54.162 UM,  
NOTE Confidence: 0.940811875714286

00:05:54.162 --> 00:05:56.018 and you can think about it like this.  
NOTE Confidence: 0.940811875714286

00:05:56.020 --> 00:05:56.869 At the top,  
NOTE Confidence: 0.940811875714286

00:05:56.869 --> 00:05:59.726 we have basically all of the ways that we

NOTE Confidence: 0.940811875714286

00:05:59.726 --> 00:06:02.138 can engage in health related communication,

NOTE Confidence: 0.940811875714286

00:06:02.140 --> 00:06:04.576 including older or more traditional modes,

NOTE Confidence: 0.940811875714286

00:06:04.580 --> 00:06:05.896 offline interactions,

NOTE Confidence: 0.940811875714286

00:06:05.896 --> 00:06:08.528 face to face interactions.

NOTE Confidence: 0.940811875714286

00:06:08.530 --> 00:06:11.162 Under that we have all the digital forms

NOTE Confidence: 0.940811875714286

00:06:11.162 --> 00:06:12.918 of communication related to health,

NOTE Confidence: 0.940811875714286

00:06:12.920 --> 00:06:15.140 and then within that digital group

NOTE Confidence: 0.940811875714286

00:06:15.140 --> 00:06:16.620 is social media specifically,

NOTE Confidence: 0.940811875714286

00:06:16.620 --> 00:06:18.260 and the definition that I

NOTE Confidence: 0.940811875714286

00:06:18.260 --> 00:06:19.900 have used for social media

NOTE Confidence: 0.948940037692308

00:06:19.964 --> 00:06:21.417 in my research. And this certainly

NOTE Confidence: 0.948940037692308

00:06:21.417 --> 00:06:22.600 isn't the be all and end all,

NOTE Confidence: 0.948940037692308

00:06:22.600 --> 00:06:24.413 but I think this is a pretty

NOTE Confidence: 0.948940037692308

00:06:24.413 --> 00:06:25.450 good and comprehensive one.

NOTE Confidence: 0.948940037692308

00:06:25.450 --> 00:06:28.229 Is that social media is all the

NOTE Confidence: 0.948940037692308

00:06:28.229 --> 00:06:30.200 websites and applications that enable  
NOTE Confidence: 0.948940037692308

00:06:30.200 --> 00:06:32.685 users to create and share content or  
NOTE Confidence: 0.948940037692308

00:06:32.685 --> 00:06:35.408 to participate in social networking.  
NOTE Confidence: 0.948940037692308

00:06:35.410 --> 00:06:37.882 And the key feature is really that there  
NOTE Confidence: 0.948940037692308

00:06:37.882 --> 00:06:40.437 is dynamic creation and sharing happening.  
NOTE Confidence: 0.948940037692308

00:06:40.440 --> 00:06:42.272 People aren't just passively  
NOTE Confidence: 0.948940037692308

00:06:42.272 --> 00:06:44.104 seeking and obtaining information,  
NOTE Confidence: 0.948940037692308

00:06:44.110 --> 00:06:45.121 they're actually producing  
NOTE Confidence: 0.948940037692308

00:06:45.121 --> 00:06:46.469 their own content too,  
NOTE Confidence: 0.948940037692308

00:06:46.470 --> 00:06:48.675 and that will become really  
NOTE Confidence: 0.948940037692308

00:06:48.675 --> 00:06:49.557 important shortly.  
NOTE Confidence: 0.948940037692308

00:06:49.560 --> 00:06:51.475 There are many within that  
NOTE Confidence: 0.948940037692308

00:06:51.475 --> 00:06:53.390 that group of social media.  
NOTE Confidence: 0.948940037692308

00:06:53.390 --> 00:06:55.120 There's many different types of  
NOTE Confidence: 0.948940037692308

00:06:55.120 --> 00:06:57.070 activities that people can engage in.  
NOTE Confidence: 0.948940037692308

00:06:57.070 --> 00:06:58.905 Elizabeth Gage Bouchard at the

NOTE Confidence: 0.948940037692308

00:06:58.905 --> 00:07:01.062 University of Rochester has done quite

NOTE Confidence: 0.948940037692308

00:07:01.062 --> 00:07:03.158 a bit of work on this and defined

NOTE Confidence: 0.948940037692308

00:07:03.158 --> 00:07:05.230 these three categories specifically,

NOTE Confidence: 0.948940037692308

00:07:05.230 --> 00:07:07.145 and they are information seeking

NOTE Confidence: 0.948940037692308

00:07:07.145 --> 00:07:09.060 material and financial support and

NOTE Confidence: 0.948940037692308

00:07:09.120 --> 00:07:11.180 psychosocial support and connection.

NOTE Confidence: 0.948940037692308

00:07:11.180 --> 00:07:12.812 And then you'll see as you go through

NOTE Confidence: 0.948940037692308

00:07:12.812 --> 00:07:14.737 as we go through some of my data that

NOTE Confidence: 0.948940037692308

00:07:14.737 --> 00:07:16.479 most of what parents are telling me

NOTE Confidence: 0.948940037692308

00:07:16.479 --> 00:07:20.310 fits within these three groups as well.

NOTE Confidence: 0.948940037692308

00:07:20.310 --> 00:07:22.570 What's that social media apart?

NOTE Confidence: 0.948940037692308

00:07:22.570 --> 00:07:23.488 UM, so these.

NOTE Confidence: 0.948940037692308

00:07:23.488 --> 00:07:26.089 These are the three things that I have

NOTE Confidence: 0.948940037692308

00:07:26.089 --> 00:07:28.016 defined from my work and my research.

NOTE Confidence: 0.948940037692308

00:07:28.020 --> 00:07:29.670 In my conversations with families,

NOTE Confidence: 0.948940037692308

00:07:29.670 --> 00:07:30.598 there may be others,  
NOTE Confidence: 0.948940037692308

00:07:30.598 --> 00:07:32.280 but I think these are pretty good.  
NOTE Confidence: 0.948940037692308

00:07:32.280 --> 00:07:35.250 Pretty good overall comprehensive categories.  
NOTE Confidence: 0.948940037692308

00:07:35.250 --> 00:07:35.597 First,  
NOTE Confidence: 0.948940037692308

00:07:35.597 --> 00:07:37.332 it's that families don't need  
NOTE Confidence: 0.948940037692308

00:07:37.332 --> 00:07:39.615 to actively seek out support or  
NOTE Confidence: 0.948940037692308

00:07:39.615 --> 00:07:41.279 support groups online anymore.  
NOTE Confidence: 0.948940037692308

00:07:41.280 --> 00:07:43.779 Social media uses a part of their  
NOTE Confidence: 0.948940037692308

00:07:43.779 --> 00:07:45.510 regularly daily daily activity,  
NOTE Confidence: 0.948940037692308

00:07:45.510 --> 00:07:47.330 and for most of the families of  
NOTE Confidence: 0.948940037692308

00:07:47.330 --> 00:07:49.000 children with cancer or families of  
NOTE Confidence: 0.948940037692308

00:07:49.000 --> 00:07:50.680 children with any serious disease or  
NOTE Confidence: 0.948940037692308

00:07:50.680 --> 00:07:52.510 even an ordinary childhood illness.  
NOTE Confidence: 0.948940037692308

00:07:52.510 --> 00:07:54.575 I talked to they say posting about  
NOTE Confidence: 0.948940037692308

00:07:54.575 --> 00:07:56.630 that was not something they did  
NOTE Confidence: 0.948940037692308

00:07:56.630 --> 00:07:58.844 just because their child got sick.

NOTE Confidence: 0.948940037692308  
00:07:58.850 --> 00:08:00.628 It was something they were already doing.  
NOTE Confidence: 0.948940037692308  
00:08:00.630 --> 00:08:02.300 They were already sharing their  
NOTE Confidence: 0.948940037692308  
00:08:02.300 --> 00:08:03.804 children's activities. They were already.  
NOTE Confidence: 0.948940037692308  
00:08:03.804 --> 00:08:05.472 They already belong to parent groups.  
NOTE Confidence: 0.948940037692308  
00:08:05.480 --> 00:08:07.112 They already exchanged Facebook  
NOTE Confidence: 0.948940037692308  
00:08:07.112 --> 00:08:09.152 posts with family members online  
NOTE Confidence: 0.948940037692308  
00:08:09.152 --> 00:08:10.770 and followed relatives,  
NOTE Confidence: 0.948940037692308  
00:08:10.770 --> 00:08:12.042 so incorporating the experience  
NOTE Confidence: 0.948940037692308  
00:08:12.042 --> 00:08:14.545 of having a sick child or needing  
NOTE Confidence: 0.948940037692308  
00:08:14.545 --> 00:08:16.138 additional health information.  
NOTE Confidence: 0.948940037692308  
00:08:16.140 --> 00:08:17.640 Wanting to find things out fits  
NOTE Confidence: 0.948940037692308  
00:08:17.640 --> 00:08:18.910 in really naturally with that.  
NOTE Confidence: 0.948940037692308  
00:08:18.910 --> 00:08:21.934 It doesn't take a lot of additional effort.  
NOTE Confidence: 0.948940037692308  
00:08:21.940 --> 00:08:23.152 The second is that,  
NOTE Confidence: 0.948940037692308  
00:08:23.152 --> 00:08:25.469 as I mentioned that on social media  
NOTE Confidence: 0.948940037692308

00:08:25.469 --> 00:08:27.174 families are creators, producers,  
NOTE Confidence: 0.948940037692308

00:08:27.174 --> 00:08:28.790 and managers of information.  
NOTE Confidence: 0.948940037692308

00:08:28.790 --> 00:08:31.292 They're not just recipients and the  
NOTE Confidence: 0.948940037692308

00:08:31.292 --> 00:08:34.109 information is just in time to borrow,  
NOTE Confidence: 0.948940037692308

00:08:34.110 --> 00:08:35.835 borrow a popular phrase for  
NOTE Confidence: 0.948940037692308

00:08:35.835 --> 00:08:36.525 medical education.  
NOTE Confidence: 0.948940037692308

00:08:36.530 --> 00:08:38.210 It's the information they want  
NOTE Confidence: 0.948940037692308

00:08:38.210 --> 00:08:40.590 when they want it very immediate.  
NOTE Confidence: 0.948940037692308

00:08:40.590 --> 00:08:43.146 It's targeted to their specific concerns.  
NOTE Confidence: 0.948940037692308

00:08:43.150 --> 00:08:44.750 It's not as general as,  
NOTE Confidence: 0.948940037692308

00:08:44.750 --> 00:08:45.050 say,  
NOTE Confidence: 0.948940037692308

00:08:45.050 --> 00:08:46.850 going on WebMD and looking up  
NOTE Confidence: 0.948940037692308

00:08:46.850 --> 00:08:48.799 an entire page about a disease.  
NOTE Confidence: 0.948940037692308

00:08:48.800 --> 00:08:51.815 It can be as specific as saying on Facebook.  
NOTE Confidence: 0.948940037692308

00:08:51.820 --> 00:08:53.620 A child is having this symptom right now.  
NOTE Confidence: 0.948940037692308

00:08:53.620 --> 00:08:54.812 What should I do?

NOTE Confidence: 0.948940037692308  
00:08:54.812 --> 00:08:56.940 And it's tailored to their parental role,  
NOTE Confidence: 0.948940037692308  
00:08:56.940 --> 00:08:58.725 so it's it's not information  
NOTE Confidence: 0.948940037692308  
00:08:58.725 --> 00:08:59.796 meant for everybody.  
NOTE Confidence: 0.948940037692308  
00:08:59.800 --> 00:09:01.608 It's often information really  
NOTE Confidence: 0.948940037692308  
00:09:01.608 --> 00:09:03.416 geared towards parents specifically,  
NOTE Confidence: 0.948940037692308  
00:09:03.420 --> 00:09:05.580 or even grandparents or other caregivers.  
NOTE Confidence: 0.948940037692308  
00:09:05.580 --> 00:09:08.009 If you want information as a stepparent,  
NOTE Confidence: 0.948940037692308  
00:09:08.010 --> 00:09:09.674 you can find that I was on a  
NOTE Confidence: 0.948940037692308  
00:09:09.674 --> 00:09:11.450 on a parenting group recently  
NOTE Confidence: 0.948940037692308  
00:09:11.450 --> 00:09:13.178 where the question was,  
NOTE Confidence: 0.894187625  
00:09:13.180 --> 00:09:15.556 I am the stepparent to a transgender child.  
NOTE Confidence: 0.894187625  
00:09:15.560 --> 00:09:17.135 How can I be supportive of them?  
NOTE Confidence: 0.894187625  
00:09:17.140 --> 00:09:19.000 But this is very specific and  
NOTE Confidence: 0.894187625  
00:09:19.000 --> 00:09:21.500 very tailored in a way that other  
NOTE Confidence: 0.894187625  
00:09:21.500 --> 00:09:23.088 types of online information.  
NOTE Confidence: 0.894187625

00:09:23.090 --> 00:09:24.710 And certainly offline  
NOTE Confidence: 0.894187625

00:09:24.710 --> 00:09:26.870 information often is not.  
NOTE Confidence: 0.894187625

00:09:26.870 --> 00:09:29.474 And finally, social media  
NOTE Confidence: 0.894187625

00:09:29.474 --> 00:09:31.427 platforms democratize information,  
NOTE Confidence: 0.894187625

00:09:31.430 --> 00:09:34.410 so they start very incompletely  
NOTE Confidence: 0.894187625

00:09:34.410 --> 00:09:35.802 and somewhat still inequitably,  
NOTE Confidence: 0.894187625

00:09:35.802 --> 00:09:38.283 but they start to level that playing  
NOTE Confidence: 0.894187625

00:09:38.283 --> 00:09:40.269 field and to allow families to  
NOTE Confidence: 0.894187625

00:09:40.269 --> 00:09:42.098 come into clinical encounters more  
NOTE Confidence: 0.894187625

00:09:42.098 --> 00:09:44.432 knowledgeable and more informed and more  
NOTE Confidence: 0.894187625

00:09:44.432 --> 00:09:46.440 willing to challenge their providers.  
NOTE Confidence: 0.937175073571429

00:09:48.870 --> 00:09:51.586 I suspect that you could put together  
NOTE Confidence: 0.937175073571429

00:09:51.586 --> 00:09:54.370 a similar slide for any disease come,  
NOTE Confidence: 0.937175073571429

00:09:54.370 --> 00:09:56.778 and probably in adults as well as Pediatrics.  
NOTE Confidence: 0.937175073571429

00:09:56.780 --> 00:09:58.430 So what I'm really saying is,  
NOTE Confidence: 0.937175073571429

00:09:58.430 --> 00:10:00.030 I think there's an information

NOTE Confidence: 0.937175073571429  
00:10:00.030 --> 00:10:01.991 mismatch everywhere that if you picked  
NOTE Confidence: 0.937175073571429  
00:10:01.991 --> 00:10:03.815 any topic and asked doctors what  
NOTE Confidence: 0.937175073571429  
00:10:03.815 --> 00:10:05.460 they think patients want to know,  
NOTE Confidence: 0.937175073571429  
00:10:05.460 --> 00:10:07.336 or other health care professionals or what  
NOTE Confidence: 0.937175073571429  
00:10:07.336 --> 00:10:09.377 they should know or what they need to know,  
NOTE Confidence: 0.937175073571429  
00:10:09.380 --> 00:10:10.635 that would be different than  
NOTE Confidence: 0.937175073571429  
00:10:10.635 --> 00:10:11.890 when you ask the patients.  
NOTE Confidence: 0.937175073571429  
00:10:11.890 --> 00:10:13.430 But specifically, in my world,  
NOTE Confidence: 0.937175073571429  
00:10:13.430 --> 00:10:15.440 in pediatric oncology there are many  
NOTE Confidence: 0.937175073571429  
00:10:15.440 --> 00:10:17.262 studies showing that we oncologists  
NOTE Confidence: 0.937175073571429  
00:10:17.262 --> 00:10:19.357 are concerned about the distress.  
NOTE Confidence: 0.937175073571429  
00:10:19.360 --> 00:10:20.212 Because families,  
NOTE Confidence: 0.937175073571429  
00:10:20.212 --> 00:10:22.768 when we give them prognostic information,  
NOTE Confidence: 0.937175073571429  
00:10:22.770 --> 00:10:25.444 or particularly when we have very uncertain  
NOTE Confidence: 0.937175073571429  
00:10:25.444 --> 00:10:27.200 prognostic information to give them,  
NOTE Confidence: 0.937175073571429

00:10:27.200 --> 00:10:29.175 and we're concerned about overwhelming

NOTE Confidence: 0.937175073571429

00:10:29.175 --> 00:10:30.360 families with information,

NOTE Confidence: 0.937175073571429

00:10:30.360 --> 00:10:31.940 especially information about late effects

NOTE Confidence: 0.937175073571429

00:10:31.940 --> 00:10:34.360 early in the course of their treatment.

NOTE Confidence: 0.937175073571429

00:10:34.360 --> 00:10:35.524 At the same time,

NOTE Confidence: 0.937175073571429

00:10:35.524 --> 00:10:37.314 there are studies that show 85%

NOTE Confidence: 0.937175073571429

00:10:37.314 --> 00:10:39.652 of our parents say they want as

NOTE Confidence: 0.937175073571429

00:10:39.652 --> 00:10:41.818 much detail as possible upfront,

NOTE Confidence: 0.937175073571429

00:10:41.820 --> 00:10:44.160 about 25% of our patients.

NOTE Confidence: 0.937175073571429

00:10:44.160 --> 00:10:46.176 Parents say they want more information

NOTE Confidence: 0.937175073571429

00:10:46.176 --> 00:10:48.159 about prognosis at every time point.

NOTE Confidence: 0.937175073571429

00:10:48.160 --> 00:10:49.380 Every time they interact with.

NOTE Confidence: 0.937175073571429

00:10:49.380 --> 00:10:49.768 Yes,

NOTE Confidence: 0.937175073571429

00:10:49.768 --> 00:10:50.544 and interestingly,

NOTE Confidence: 0.937175073571429

00:10:50.544 --> 00:10:52.872 families who are more upset about

NOTE Confidence: 0.937175073571429

00:10:52.872 --> 00:10:55.145 the information or find it more

NOTE Confidence: 0.937175073571429

00:10:55.145 --> 00:10:56.960 distressing are also the ones

NOTE Confidence: 0.937175073571429

00:10:57.026 --> 00:10:58.804 who tend to want more of it.

NOTE Confidence: 0.937175073571429

00:10:58.810 --> 00:11:00.496 So there's a disconnect there between

NOTE Confidence: 0.937175073571429

00:11:00.496 --> 00:11:02.101 what we think families want to

NOTE Confidence: 0.937175073571429

00:11:02.101 --> 00:11:03.592 hear from West and what they say,

NOTE Confidence: 0.937175073571429

00:11:03.600 --> 00:11:05.728 and that's a disconnect that can be

NOTE Confidence: 0.937175073571429

00:11:05.728 --> 00:11:08.021 resolved on social media on social media.

NOTE Confidence: 0.937175073571429

00:11:08.021 --> 00:11:09.756 Families can access information in

NOTE Confidence: 0.937175073571429

00:11:09.756 --> 00:11:12.048 their own time and at their own pace,

NOTE Confidence: 0.937175073571429

00:11:12.050 --> 00:11:13.838 so they have more control over

NOTE Confidence: 0.937175073571429

00:11:13.838 --> 00:11:15.547 the flow of information than they

NOTE Confidence: 0.937175073571429

00:11:15.547 --> 00:11:17.136 do in an exam room with us,

NOTE Confidence: 0.937175073571429

00:11:17.140 --> 00:11:19.388 where we may check in periodically and say.

NOTE Confidence: 0.937175073571429

00:11:19.390 --> 00:11:20.545 Do you want to take a break?

NOTE Confidence: 0.937175073571429

00:11:20.550 --> 00:11:22.465 But we're often deciding the

NOTE Confidence: 0.937175073571429

00:11:22.465 --> 00:11:24.380 bounds of what information they're  
NOTE Confidence: 0.937175073571429

00:11:24.448 --> 00:11:25.908 getting in that session.  
NOTE Confidence: 0.937175073571429

00:11:25.910 --> 00:11:28.598 Some families may be more willing to ask  
NOTE Confidence: 0.937175073571429

00:11:28.598 --> 00:11:30.679 questions that are perceived as dumb,  
NOTE Confidence: 0.937175073571429

00:11:30.680 --> 00:11:32.976 even labeled as done by the families  
NOTE Confidence: 0.937175073571429

00:11:32.976 --> 00:11:34.752 themselves when they're talking to  
NOTE Confidence: 0.937175073571429

00:11:34.752 --> 00:11:36.582 other families rather than health  
NOTE Confidence: 0.937175073571429

00:11:36.582 --> 00:11:38.519 care professionals and other families  
NOTE Confidence: 0.937175073571429

00:11:38.519 --> 00:11:40.459 are absolutely more equipped to  
NOTE Confidence: 0.937175073571429

00:11:40.459 --> 00:11:42.806 provide pragmatic advice to help other  
NOTE Confidence: 0.937175073571429

00:11:42.806 --> 00:11:44.766 families with children with similar  
NOTE Confidence: 0.937175073571429

00:11:44.766 --> 00:11:46.668 conditions figure out feeding sleep.  
NOTE Confidence: 0.937175073571429

00:11:46.670 --> 00:11:49.040 Some of these other parenting things,  
NOTE Confidence: 0.937175073571429

00:11:49.040 --> 00:11:50.672 and the production of that information  
NOTE Confidence: 0.937175073571429

00:11:50.672 --> 00:11:53.053 is a is a pretty meaningful psychosocial  
NOTE Confidence: 0.937175073571429

00:11:53.053 --> 00:11:55.916 benefit for the families who are sharing.

NOTE Confidence: 0.937175073571429

00:11:55.920 --> 00:11:58.398 Who are able to help other people

NOTE Confidence: 0.937175073571429

00:11:58.398 --> 00:12:00.760 going through what they went through?

NOTE Confidence: 0.937175073571429

00:12:00.760 --> 00:12:02.824 From many different studies we have

NOTE Confidence: 0.937175073571429

00:12:02.824 --> 00:12:05.292 found that our people have found that

NOTE Confidence: 0.937175073571429

00:12:05.292 --> 00:12:07.356 parents and adult patients who use

NOTE Confidence: 0.937175073571429

00:12:07.356 --> 00:12:09.448 social media for health information

NOTE Confidence: 0.937175073571429

00:12:09.450 --> 00:12:11.850 report greater feelings of empowerment,

NOTE Confidence: 0.937175073571429

00:12:11.850 --> 00:12:12.510 more control,

NOTE Confidence: 0.937175073571429

00:12:12.510 --> 00:12:14.490 a sense of competence that they

NOTE Confidence: 0.937175073571429

00:12:14.490 --> 00:12:16.406 feel better equipped to advocate

NOTE Confidence: 0.937175073571429

00:12:16.406 --> 00:12:18.396 for themselves and their children,

NOTE Confidence: 0.937175073571429

00:12:18.400 --> 00:12:20.318 and that they may even have better

NOTE Confidence: 0.937175073571429

00:12:20.318 --> 00:12:21.579 adherence and possibly improve

NOTE Confidence: 0.937175073571429

00:12:21.579 --> 00:12:22.349 health outcomes.

NOTE Confidence: 0.937175073571429

00:12:22.350 --> 00:12:24.312 There's some evidence in the adult

NOTE Confidence: 0.937175073571429

00:12:24.312 --> 00:12:25.513 literature that using social  
NOTE Confidence: 0.937175073571429

00:12:25.513 --> 00:12:27.259 media does help in that way.  
NOTE Confidence: 0.922229865909091

00:12:29.420 --> 00:12:30.648 At the same time,  
NOTE Confidence: 0.922229865909091

00:12:30.648 --> 00:12:33.367 I wanted to give you all a sense  
NOTE Confidence: 0.922229865909091

00:12:33.367 --> 00:12:35.779 of just how complex these these  
NOTE Confidence: 0.922229865909091

00:12:35.779 --> 00:12:37.899 connections and interactions are,  
NOTE Confidence: 0.922229865909091

00:12:37.900 --> 00:12:40.060 because I'm not really just talking  
NOTE Confidence: 0.922229865909091

00:12:40.060 --> 00:12:42.100 about patients and their caregivers  
NOTE Confidence: 0.922229865909091

00:12:42.100 --> 00:12:44.260 interacting with other caregivers,  
NOTE Confidence: 0.922229865909091

00:12:44.260 --> 00:12:45.496 and they certainly are.  
NOTE Confidence: 0.922229865909091

00:12:45.496 --> 00:12:47.041 They're certainly talking to other  
NOTE Confidence: 0.922229865909091

00:12:47.041 --> 00:12:48.621 people who have children with the  
NOTE Confidence: 0.922229865909091

00:12:48.621 --> 00:12:50.170 same disease or the same issue.  
NOTE Confidence: 0.922229865909091

00:12:50.170 --> 00:12:51.394 They're talking to their  
NOTE Confidence: 0.922229865909091

00:12:51.394 --> 00:12:52.618 own family and friends.  
NOTE Confidence: 0.922229865909091

00:12:52.620 --> 00:12:53.583 Sometimes they're talking

NOTE Confidence: 0.922229865909091  
00:12:53.583 --> 00:12:54.867 to their health providers,  
NOTE Confidence: 0.922229865909091  
00:12:54.870 --> 00:12:56.205 depending on whether or not  
NOTE Confidence: 0.922229865909091  
00:12:56.205 --> 00:12:57.893 their health care provider has a  
NOTE Confidence: 0.922229865909091  
00:12:57.893 --> 00:12:59.109 professional website or allows.  
NOTE Confidence: 0.922229865909091  
00:12:59.110 --> 00:13:00.532 Personal contact outside  
NOTE Confidence: 0.922229865909091  
00:13:00.532 --> 00:13:02.428 of a professional website.  
NOTE Confidence: 0.922229865909091  
00:13:02.430 --> 00:13:04.726 They may be reaching out to new  
NOTE Confidence: 0.922229865909091  
00:13:04.726 --> 00:13:06.465 health care providers that they  
NOTE Confidence: 0.922229865909091  
00:13:06.465 --> 00:13:08.190 had no prior relationship to,  
NOTE Confidence: 0.922229865909091  
00:13:08.190 --> 00:13:10.062 or they may be connecting with  
NOTE Confidence: 0.922229865909091  
00:13:10.062 --> 00:13:11.310 other health care institutions.  
NOTE Confidence: 0.922229865909091  
00:13:11.310 --> 00:13:12.994 Other individuals with professional  
NOTE Confidence: 0.922229865909091  
00:13:12.994 --> 00:13:14.257 interests and expertise,  
NOTE Confidence: 0.922229865909091  
00:13:14.260 --> 00:13:15.388 and organizational groups.  
NOTE Confidence: 0.922229865909091  
00:13:15.388 --> 00:13:17.268 So I think it's important,  
NOTE Confidence: 0.922229865909091

00:13:17.270 --> 00:13:19.118 especially as we get into the ethics  
NOTE Confidence: 0.922229865909091

00:13:19.118 --> 00:13:21.123 of this space that we don't forget  
NOTE Confidence: 0.922229865909091

00:13:21.123 --> 00:13:23.290 about the presence of other groups online,  
NOTE Confidence: 0.922229865909091

00:13:23.290 --> 00:13:24.184 especially industry groups,  
NOTE Confidence: 0.922229865909091

00:13:24.184 --> 00:13:26.804 and that all of these people can be in  
NOTE Confidence: 0.922229865909091

00:13:26.804 --> 00:13:28.470 contact with each other at all times.  
NOTE Confidence: 0.922229865909091

00:13:28.470 --> 00:13:29.586 Any of these?  
NOTE Confidence: 0.922229865909091

00:13:29.586 --> 00:13:32.190 Interactions can be one way or bi  
NOTE Confidence: 0.922229865909091

00:13:32.274 --> 00:13:34.890 directional or multi directional.  
NOTE Confidence: 0.922229865909091

00:13:34.890 --> 00:13:37.100 So how might social media  
NOTE Confidence: 0.922229865909091

00:13:37.100 --> 00:13:38.868 influence our clinical encounters?  
NOTE Confidence: 0.922229865909091

00:13:38.870 --> 00:13:41.374 So this came out of our our first  
NOTE Confidence: 0.922229865909091

00:13:41.374 --> 00:13:42.977 social media study in 2016,  
NOTE Confidence: 0.922229865909091

00:13:42.977 --> 00:13:45.476 which was a series of surveys and  
NOTE Confidence: 0.922229865909091

00:13:45.476 --> 00:13:47.494 then interviews with pediatric  
NOTE Confidence: 0.922229865909091

00:13:47.494 --> 00:13:48.728 oncology professionals,

NOTE Confidence: 0.922229865909091  
00:13:48.730 --> 00:13:51.080 and we identified this these  
NOTE Confidence: 0.922229865909091  
00:13:51.080 --> 00:13:52.020 potential pathways.  
NOTE Confidence: 0.922229865909091  
00:13:52.020 --> 00:13:53.388 So before the visit,  
NOTE Confidence: 0.922229865909091  
00:13:53.388 --> 00:13:55.098 parents might be using social  
NOTE Confidence: 0.922229865909091  
00:13:55.098 --> 00:13:57.038 media to select their provider.  
NOTE Confidence: 0.922229865909091  
00:13:57.040 --> 00:13:59.200 So looking at our reviews online  
NOTE Confidence: 0.922229865909091  
00:13:59.200 --> 00:14:01.168 or asking other families about  
NOTE Confidence: 0.922229865909091  
00:14:01.168 --> 00:14:03.458 the reputation of certain health  
NOTE Confidence: 0.922229865909091  
00:14:03.458 --> 00:14:04.374 care professionals.  
NOTE Confidence: 0.922229865909091  
00:14:04.380 --> 00:14:06.245 They might be acquiring background  
NOTE Confidence: 0.922229865909091  
00:14:06.245 --> 00:14:07.737 information related to their  
NOTE Confidence: 0.922229865909091  
00:14:07.737 --> 00:14:09.539 child's condition on social media,  
NOTE Confidence: 0.922229865909091  
00:14:09.540 --> 00:14:11.454 and they might be already seeking  
NOTE Confidence: 0.922229865909091  
00:14:11.454 --> 00:14:13.235 some support or learning about  
NOTE Confidence: 0.922229865909091  
00:14:13.235 --> 00:14:14.999 other families experiences online,  
NOTE Confidence: 0.922229865909091

00:14:15.000 --> 00:14:16.385 depending on what the child's  
NOTE Confidence: 0.922229865909091

00:14:16.385 --> 00:14:17.216 medical condition is,  
NOTE Confidence: 0.922229865909091

00:14:17.220 --> 00:14:19.936 what the problem is during the visit,  
NOTE Confidence: 0.922229865909091

00:14:19.940 --> 00:14:21.720 they may be asking clinicians  
NOTE Confidence: 0.922229865909091

00:14:21.720 --> 00:14:23.954 opinion of information or asking for  
NOTE Confidence: 0.922229865909091

00:14:23.954 --> 00:14:25.538 interventions based on information  
NOTE Confidence: 0.922229865909091

00:14:25.538 --> 00:14:27.518 that they brought from online,  
NOTE Confidence: 0.922229865909091

00:14:27.520 --> 00:14:29.550 and they might become more or less  
NOTE Confidence: 0.922229865909091

00:14:29.550 --> 00:14:31.717 anxious based on that information based  
NOTE Confidence: 0.922229865909091

00:14:31.717 --> 00:14:34.183 on clinicians response to their questions.  
NOTE Confidence: 0.922229865909091

00:14:34.190 --> 00:14:35.595 And the support they received  
NOTE Confidence: 0.922229865909091

00:14:35.595 --> 00:14:37.294 they also and I'll come back  
NOTE Confidence: 0.922229865909091

00:14:37.294 --> 00:14:38.960 to this in the ethics they may  
NOTE Confidence: 0.922229865909091

00:14:38.960 --> 00:14:40.560 ask about other patients care,  
NOTE Confidence: 0.922229865909091

00:14:40.560 --> 00:14:42.611 especially if this is a center where  
NOTE Confidence: 0.922229865909091

00:14:42.611 --> 00:14:44.695 they know other families who are

NOTE Confidence: 0.922229865909091  
00:14:44.695 --> 00:14:46.600 being treated for similar conditions.  
NOTE Confidence: 0.922229865909091  
00:14:46.600 --> 00:14:47.232 And finally,  
NOTE Confidence: 0.922229865909091  
00:14:47.232 --> 00:14:49.128 after the visit they may post  
NOTE Confidence: 0.922229865909091  
00:14:49.128 --> 00:14:50.832 online reviews or informally share  
NOTE Confidence: 0.922229865909091  
00:14:50.832 --> 00:14:52.860 their opinion of the visit online  
NOTE Confidence: 0.922229865909091  
00:14:52.860 --> 00:14:54.590 telling other families go there.  
NOTE Confidence: 0.922229865909091  
00:14:54.590 --> 00:14:56.526 Don't go there. We had a bad experience.  
NOTE Confidence: 0.922229865909091  
00:14:56.530 --> 00:14:57.894 You should do this.  
NOTE Confidence: 0.922229865909091  
00:14:57.894 --> 00:14:59.599 They might verify the clinicians  
NOTE Confidence: 0.922229865909091  
00:14:59.599 --> 00:15:01.510 advice on social media and ultimately  
NOTE Confidence: 0.922229865909091  
00:15:01.510 --> 00:15:03.652 they might be more or less able  
NOTE Confidence: 0.922229865909091  
00:15:03.652 --> 00:15:05.386 to cope with the diagnosis and  
NOTE Confidence: 0.922229865909091  
00:15:05.386 --> 00:15:07.802 adhere to treatment based on how  
NOTE Confidence: 0.922229865909091  
00:15:07.802 --> 00:15:10.092 all of this plays out.  
NOTE Confidence: 0.922229865909091  
00:15:10.100 --> 00:15:12.647 Some of that pause on that for a moment  
NOTE Confidence: 0.922229865909091

00:15:12.647 --> 00:15:15.175 and tell you about our current study,  
NOTE Confidence: 0.922229865909091

00:15:15.180 --> 00:15:16.930 because throughout the rest of the talk,  
NOTE Confidence: 0.922229865909091

00:15:16.930 --> 00:15:18.538 I'm going to present both some  
NOTE Confidence: 0.922229865909091

00:15:18.538 --> 00:15:19.971 data that we've already published  
NOTE Confidence: 0.922229865909091

00:15:19.971 --> 00:15:21.531 in some unpublished data and  
NOTE Confidence: 0.922229865909091

00:15:21.531 --> 00:15:22.779 discuss some things that  
NOTE Confidence: 0.931667564074074

00:15:22.835 --> 00:15:24.816 we're still in the process of analyzing.  
NOTE Confidence: 0.931667564074074

00:15:24.820 --> 00:15:26.773 So this is a mixed method study  
NOTE Confidence: 0.931667564074074

00:15:26.773 --> 00:15:28.744 that we've used written online  
NOTE Confidence: 0.931667564074074

00:15:28.744 --> 00:15:30.349 questionnaires and interviews,  
NOTE Confidence: 0.931667564074074

00:15:30.350 --> 00:15:32.149 and all parents of children with cancer  
NOTE Confidence: 0.931667564074074

00:15:32.149 --> 00:15:34.357 who had ever used social media for  
NOTE Confidence: 0.931667564074074

00:15:34.357 --> 00:15:36.087 health related information were eligible,  
NOTE Confidence: 0.931667564074074

00:15:36.090 --> 00:15:37.878 as well as their pediatric oncologists.  
NOTE Confidence: 0.931667564074074

00:15:37.880 --> 00:15:39.406 So we actually asked them to nominate.  
NOTE Confidence: 0.931667564074074

00:15:39.410 --> 00:15:42.347 Their own oncologists to participate and

NOTE Confidence: 0.931667564074074

00:15:42.347 --> 00:15:44.532 we recruited mainly through nonprofits

NOTE Confidence: 0.931667564074074

00:15:44.532 --> 00:15:47.449 that had a social media presence.

NOTE Confidence: 0.931667564074074

00:15:47.450 --> 00:15:49.664 So the goal of the study was to describe

NOTE Confidence: 0.931667564074074

00:15:49.664 --> 00:15:51.849 how parents and family is evaluate the

NOTE Confidence: 0.931667564074074

00:15:51.849 --> 00:15:54.230 benefits and risks of using social media,

NOTE Confidence: 0.931667564074074

00:15:54.230 --> 00:15:56.502 including what ethical issues

NOTE Confidence: 0.931667564074074

00:15:56.502 --> 00:15:58.206 they themselves identify,

NOTE Confidence: 0.931667564074074

00:15:58.210 --> 00:15:59.978 how they navigate disagreements

NOTE Confidence: 0.931667564074074

00:15:59.978 --> 00:16:01.746 between their oncologists advice

NOTE Confidence: 0.931667564074074

00:16:01.746 --> 00:16:03.648 and information found on social

NOTE Confidence: 0.931667564074074

00:16:03.648 --> 00:16:05.238 media and for the oncologists,

NOTE Confidence: 0.931667564074074

00:16:05.240 --> 00:16:06.680 how they navigate,

NOTE Confidence: 0.931667564074074

00:16:06.680 --> 00:16:08.600 conflict and disagreement related

NOTE Confidence: 0.931667564074074

00:16:08.600 --> 00:16:10.040 to social media.

NOTE Confidence: 0.931667564074074

00:16:10.040 --> 00:16:11.846 So we started with the nonprofits and

NOTE Confidence: 0.931667564074074

00:16:11.846 --> 00:16:13.863 invited them to share a recruitment flyer  
NOTE Confidence: 0.931667564074074

00:16:13.863 --> 00:16:16.042 that parents could then contact our study  
NOTE Confidence: 0.931667564074074

00:16:16.042 --> 00:16:17.747 coordinator if they were interested.  
NOTE Confidence: 0.931667564074074

00:16:17.750 --> 00:16:20.288 We had 90 parents complete questionnaires.  
NOTE Confidence: 0.931667564074074

00:16:20.290 --> 00:16:22.621 That was about a year and a half ago  
NOTE Confidence: 0.931667564074074

00:16:22.621 --> 00:16:24.805 now and about a little bit over 30,  
NOTE Confidence: 0.931667564074074

00:16:24.810 --> 00:16:26.892 expressed interest on a follow up  
NOTE Confidence: 0.931667564074074

00:16:26.892 --> 00:16:28.822 interview in 22 actually completed  
NOTE Confidence: 0.931667564074074

00:16:28.822 --> 00:16:31.256 that interview and then all of  
NOTE Confidence: 0.931667564074074

00:16:31.256 --> 00:16:32.732 those nominated their oncologists  
NOTE Confidence: 0.931667564074074

00:16:32.732 --> 00:16:33.470 for participation.  
NOTE Confidence: 0.931667564074074

00:16:33.470 --> 00:16:34.961 And that's the recruitment were a little  
NOTE Confidence: 0.931667564074074

00:16:34.961 --> 00:16:36.568 bit stuck on this recruitment point.  
NOTE Confidence: 0.931667564074074

00:16:36.570 --> 00:16:39.618 We've had about eight of those  
NOTE Confidence: 0.931667564074074

00:16:39.618 --> 00:16:41.142 oncologists complete questionnaires.  
NOTE Confidence: 0.931667564074074

00:16:41.150 --> 00:16:43.120 The parent questionnaire we gathered,

NOTE Confidence: 0.931667564074074  
00:16:43.120 --> 00:16:45.160 of course, basic demographic information.  
NOTE Confidence: 0.931667564074074  
00:16:45.160 --> 00:16:48.387 We asked about general social media use.  
NOTE Confidence: 0.931667564074074  
00:16:48.390 --> 00:16:50.287 Pretty widespread and most people are most  
NOTE Confidence: 0.931667564074074  
00:16:50.287 --> 00:16:52.296 people who say they're using it at all,  
NOTE Confidence: 0.931667564074074  
00:16:52.300 --> 00:16:54.060 or using it pretty frequently.  
NOTE Confidence: 0.931667564074074  
00:16:54.060 --> 00:16:56.668 We asked about how they use social media  
NOTE Confidence: 0.931667564074074  
00:16:56.668 --> 00:16:58.660 specifically related to their child's cancer,  
NOTE Confidence: 0.931667564074074  
00:16:58.660 --> 00:17:00.636 about their experiences with  
NOTE Confidence: 0.931667564074074  
00:17:00.636 --> 00:17:02.612 disagreements and conflicting information  
NOTE Confidence: 0.931667564074074  
00:17:02.612 --> 00:17:05.049 about their understanding of trust.  
NOTE Confidence: 0.931667564074074  
00:17:05.050 --> 00:17:07.002 Because in the next part of this work  
NOTE Confidence: 0.931667564074074  
00:17:07.002 --> 00:17:08.586 were very interested in exploring  
NOTE Confidence: 0.931667564074074  
00:17:08.586 --> 00:17:10.662 how social media might affect trust,  
NOTE Confidence: 0.931667564074074  
00:17:10.670 --> 00:17:12.224 and then we also had them fill  
NOTE Confidence: 0.931667564074074  
00:17:12.224 --> 00:17:13.710 out the trusted physician scale,  
NOTE Confidence: 0.931667564074074

00:17:13.710 --> 00:17:16.664 which was mainly at check on saying  
NOTE Confidence: 0.931667564074074

00:17:16.670 --> 00:17:18.539 the population in this study is not.  
NOTE Confidence: 0.931667564074074

00:17:18.540 --> 00:17:19.704 Significantly different than other  
NOTE Confidence: 0.931667564074074

00:17:19.704 --> 00:17:21.450 parents with regard to their trust  
NOTE Confidence: 0.931667564074074

00:17:21.502 --> 00:17:23.502 in their own doctors, they're pretty.  
NOTE Confidence: 0.931667564074074

00:17:23.502 --> 00:17:25.170 They're pretty average.  
NOTE Confidence: 0.931667564074074

00:17:25.170 --> 00:17:26.874 And then in the parent interview  
NOTE Confidence: 0.931667564074074

00:17:26.874 --> 00:17:28.760 we asked some open ended questions  
NOTE Confidence: 0.931667564074074

00:17:28.760 --> 00:17:30.830 about both about their family and  
NOTE Confidence: 0.931667564074074

00:17:30.830 --> 00:17:32.030 their cancer journey,  
NOTE Confidence: 0.931667564074074

00:17:32.030 --> 00:17:33.354 about their written responses  
NOTE Confidence: 0.931667564074074

00:17:33.354 --> 00:17:34.347 to the questionnaire.  
NOTE Confidence: 0.931667564074074

00:17:34.350 --> 00:17:36.023 So getting in a little more deeply  
NOTE Confidence: 0.931667564074074

00:17:36.023 --> 00:17:37.759 to some of those experiences,  
NOTE Confidence: 0.931667564074074

00:17:37.760 --> 00:17:40.136 we have three member check questions,  
NOTE Confidence: 0.931667564074074

00:17:40.140 --> 00:17:41.526 which for those who may not do

NOTE Confidence: 0.931667564074074

00:17:41.526 --> 00:17:43.249 a lot of qualitative research,

NOTE Confidence: 0.931667564074074

00:17:43.250 --> 00:17:45.610 is a common quality measure.

NOTE Confidence: 0.931667564074074

00:17:45.610 --> 00:17:46.886 And doing qualitative research

NOTE Confidence: 0.931667564074074

00:17:46.886 --> 00:17:49.137 where we ask other members of the

NOTE Confidence: 0.931667564074074

00:17:49.137 --> 00:17:50.799 Group of the study population what

NOTE Confidence: 0.931667564074074

00:17:50.799 --> 00:17:52.748 they think of our analysis so far,

NOTE Confidence: 0.931667564074074

00:17:52.750 --> 00:17:54.311 and so we said things like some

NOTE Confidence: 0.931667564074074

00:17:54.311 --> 00:17:55.330 parents in our study.

NOTE Confidence: 0.931667564074074

00:17:55.330 --> 00:17:58.120 I've said that what do you think about that?

NOTE Confidence: 0.931667564074074

00:17:58.120 --> 00:18:00.046 And then we had three questions

NOTE Confidence: 0.931667564074074

00:18:00.046 --> 00:18:02.150 asking about their advice for other

NOTE Confidence: 0.931667564074074

00:18:02.150 --> 00:18:04.040 parents for health care professionals

NOTE Confidence: 0.931667564074074

00:18:04.040 --> 00:18:06.079 and their perceived ethical issues.

NOTE Confidence: 0.931667564074074

00:18:06.080 --> 00:18:06.826 And finally,

NOTE Confidence: 0.931667564074074

00:18:06.826 --> 00:18:09.064 the physician questionnaire was very similar.

NOTE Confidence: 0.931667564074074

00:18:09.070 --> 00:18:10.700 We looked at physicians perceptions  
NOTE Confidence: 0.931667564074074

00:18:10.700 --> 00:18:12.850 of social media's impact on medicine,  
NOTE Confidence: 0.931667564074074

00:18:12.850 --> 00:18:14.842 both personally and and at the  
NOTE Confidence: 0.931667564074074

00:18:14.842 --> 00:18:16.170 larger level of the  
NOTE Confidence: 0.877084365454545

00:18:16.244 --> 00:18:18.150 profession and their thoughts on  
NOTE Confidence: 0.877084365454545

00:18:18.150 --> 00:18:20.010 the impact on patient family trust.  
NOTE Confidence: 0.877084365454545

00:18:20.010 --> 00:18:22.215 We asked about individual and  
NOTE Confidence: 0.877084365454545

00:18:22.215 --> 00:18:23.538 institutional practices regarding  
NOTE Confidence: 0.877084365454545

00:18:23.538 --> 00:18:25.819 social media education for families.  
NOTE Confidence: 0.877084365454545

00:18:25.820 --> 00:18:27.920 Their ethical concerns and then what  
NOTE Confidence: 0.877084365454545

00:18:27.920 --> 00:18:30.157 they do when families bring health  
NOTE Confidence: 0.877084365454545

00:18:30.157 --> 00:18:32.087 information from social media into  
NOTE Confidence: 0.877084365454545

00:18:32.087 --> 00:18:34.520 their into their clinical encounters.  
NOTE Confidence: 0.877084365454545

00:18:34.520 --> 00:18:37.112 So this is a study from 2017 that  
NOTE Confidence: 0.877084365454545

00:18:37.112 --> 00:18:40.109 looked at parents and parents in Canada.  
NOTE Confidence: 0.877084365454545

00:18:40.110 --> 00:18:42.336 Kids with kidney disease and they

NOTE Confidence: 0.877084365454545

00:18:42.336 --> 00:18:45.007 saw social media as a journey where

NOTE Confidence: 0.877084365454545

00:18:45.007 --> 00:18:47.233 where people often started out in

NOTE Confidence: 0.877084365454545

00:18:47.233 --> 00:18:49.778 the pure information seeking form.

NOTE Confidence: 0.877084365454545

00:18:49.780 --> 00:18:51.970 But by the end through this

NOTE Confidence: 0.877084365454545

00:18:51.970 --> 00:18:53.065 process of interaction,

NOTE Confidence: 0.877084365454545

00:18:53.070 --> 00:18:55.075 support and collaboration really moved

NOTE Confidence: 0.877084365454545

00:18:55.075 --> 00:18:58.148 into an advocacy role and we didn't see

NOTE Confidence: 0.877084365454545

00:18:58.148 --> 00:19:00.472 quite the same trajectory in our study.

NOTE Confidence: 0.877084365454545

00:19:00.480 --> 00:19:02.780 Some parents followed that journey,

NOTE Confidence: 0.877084365454545

00:19:02.780 --> 00:19:04.400 but I think the interesting thing.

NOTE Confidence: 0.877084365454545

00:19:04.400 --> 00:19:06.926 About what parents described was how

NOTE Confidence: 0.877084365454545

00:19:06.926 --> 00:19:09.600 their reasons for using social media,

NOTE Confidence: 0.877084365454545

00:19:09.600 --> 00:19:11.588 which included everything from

NOTE Confidence: 0.877084365454545

00:19:11.588 --> 00:19:13.079 information to communication,

NOTE Confidence: 0.877084365454545

00:19:13.080 --> 00:19:14.942 lots of parents just said I couldn't

NOTE Confidence: 0.877084365454545

00:19:14.942 --> 00:19:16.719 stand to answer anymore questions,  
NOTE Confidence: 0.877084365454545

00:19:16.720 --> 00:19:18.568 and so I had to start communicating  
NOTE Confidence: 0.877084365454545

00:19:18.568 --> 00:19:20.715 with my family on mass and I did  
NOTE Confidence: 0.877084365454545

00:19:20.715 --> 00:19:22.010 it publicly on Facebook because  
NOTE Confidence: 0.877084365454545

00:19:22.066 --> 00:19:23.758 that's what I was already doing.  
NOTE Confidence: 0.877084365454545

00:19:23.760 --> 00:19:24.924 Connection for emotional  
NOTE Confidence: 0.877084365454545

00:19:24.924 --> 00:19:26.088 or practical support,  
NOTE Confidence: 0.877084365454545

00:19:26.090 --> 00:19:27.934 finding new treatment options,  
NOTE Confidence: 0.877084365454545

00:19:27.934 --> 00:19:28.856 confirming recommendations.  
NOTE Confidence: 0.877084365454545

00:19:28.860 --> 00:19:31.898 But how how they use social media  
NOTE Confidence: 0.877084365454545

00:19:31.900 --> 00:19:35.008 then lead into either an experience.  
NOTE Confidence: 0.877084365454545

00:19:35.010 --> 00:19:36.381 The greater psychological  
NOTE Confidence: 0.877084365454545

00:19:36.381 --> 00:19:38.209 safety or greater risks,  
NOTE Confidence: 0.877084365454545

00:19:38.210 --> 00:19:41.042 but parents also describe  
NOTE Confidence: 0.877084365454545

00:19:41.042 --> 00:19:43.166 greater potential rewards.  
NOTE Confidence: 0.877084365454545

00:19:43.170 --> 00:19:44.538 In an ideal world,

NOTE Confidence: 0.877084365454545

00:19:44.538 --> 00:19:47.198 I think that digital and social media

NOTE Confidence: 0.877084365454545

00:19:47.198 --> 00:19:49.878 would really enhance these relationships.

NOTE Confidence: 0.877084365454545

00:19:49.880 --> 00:19:52.418 It can give a common vocabulary

NOTE Confidence: 0.877084365454545

00:19:52.418 --> 00:19:53.687 and align expectations.

NOTE Confidence: 0.877084365454545

00:19:53.690 --> 00:19:55.904 It can increase parents confidence and

NOTE Confidence: 0.877084365454545

00:19:55.904 --> 00:19:58.001 doctors conclusions and advice talk more

NOTE Confidence: 0.877084365454545

00:19:58.001 --> 00:20:00.265 in a moment about when that doesn't happen.

NOTE Confidence: 0.877084365454545

00:20:00.270 --> 00:20:01.962 It can certainly build

NOTE Confidence: 0.877084365454545

00:20:01.962 --> 00:20:03.654 scientific and health literacy,

NOTE Confidence: 0.877084365454545

00:20:03.660 --> 00:20:05.376 and many parents said that they

NOTE Confidence: 0.877084365454545

00:20:05.376 --> 00:20:07.304 were able to ask questions because

NOTE Confidence: 0.877084365454545

00:20:07.304 --> 00:20:09.452 social media gave them the language

NOTE Confidence: 0.877084365454545

00:20:09.452 --> 00:20:11.190 to ask those questions.

NOTE Confidence: 0.877084365454545

00:20:11.190 --> 00:20:13.360 It can validate personal experience.

NOTE Confidence: 0.877084365454545

00:20:13.360 --> 00:20:16.440 And it can raise awareness and promote

NOTE Confidence: 0.877084365454545

00:20:16.440 --> 00:20:19.328 support for research programs and policy.

NOTE Confidence: 0.877084365454545

00:20:19.330 --> 00:20:20.410 At the same time,

NOTE Confidence: 0.877084365454545

00:20:20.410 --> 00:20:21.760 we have lots of concerns.

NOTE Confidence: 0.877084365454545

00:20:21.760 --> 00:20:23.550 We as health care professionals.

NOTE Confidence: 0.877084365454545

00:20:23.550 --> 00:20:25.734 These are the four main ones

NOTE Confidence: 0.877084365454545

00:20:25.734 --> 00:20:27.470 and perhaps the biggest is.

NOTE Confidence: 0.877084365454545

00:20:27.470 --> 00:20:29.370 That information will be misleading,

NOTE Confidence: 0.877084365454545

00:20:29.370 --> 00:20:30.555 inaccurate or false,

NOTE Confidence: 0.877084365454545

00:20:30.555 --> 00:20:32.925 and the COVID-19 pandemic has done

NOTE Confidence: 0.877084365454545

00:20:32.925 --> 00:20:34.889 nothing to assuage that concern.

NOTE Confidence: 0.877084365454545

00:20:34.890 --> 00:20:36.234 It's still very,

NOTE Confidence: 0.877084365454545

00:20:36.234 --> 00:20:38.474 very pervasive and very real.

NOTE Confidence: 0.877084365454545

00:20:38.480 --> 00:20:40.432 I do think it's worth noting that at

NOTE Confidence: 0.877084365454545

00:20:40.432 --> 00:20:42.164 least one study looked at accuracy

NOTE Confidence: 0.877084365454545

00:20:42.164 --> 00:20:44.272 in in Facebook posts by parents of

NOTE Confidence: 0.877084365454545

00:20:44.272 --> 00:20:45.892 children with cancer and found about

NOTE Confidence: 0.877084365454545

00:20:45.892 --> 00:20:47.610 2/3 of them were medically accurate.

NOTE Confidence: 0.877084365454545

00:20:47.610 --> 00:20:49.710 And I've always wondered if we coded.

NOTE Confidence: 0.877084365454545

00:20:49.710 --> 00:20:50.934 Our conversations with family

NOTE Confidence: 0.877084365454545

00:20:50.934 --> 00:20:52.464 is what would we find?

NOTE Confidence: 0.877084365454545

00:20:52.470 --> 00:20:54.246 I hope we would do better,

NOTE Confidence: 0.877084365454545

00:20:54.250 --> 00:20:56.346 but I fear that maybe we would be

NOTE Confidence: 0.877084365454545

00:20:56.346 --> 00:20:58.380 not not as much better as we'd

NOTE Confidence: 0.877084365454545

00:20:58.380 --> 00:21:00.080 like and and at the same time,

NOTE Confidence: 0.877084365454545

00:21:00.080 --> 00:21:01.421 addressing that misinformation

NOTE Confidence: 0.877084365454545

00:21:01.421 --> 00:21:03.209 can be really time-consuming,

NOTE Confidence: 0.877084365454545

00:21:03.210 --> 00:21:05.275 so this is a study from Australia

NOTE Confidence: 0.877084365454545

00:21:05.275 --> 00:21:05.865 that looked.

NOTE Confidence: 0.877084365454545

00:21:05.870 --> 00:21:07.850 I think it neurosurgeons and

NOTE Confidence: 0.877084365454545

00:21:07.850 --> 00:21:09.434 children with cranial deformities

NOTE Confidence: 0.877084365454545

00:21:09.434 --> 00:21:11.433 who were undergoing surgery and

NOTE Confidence: 0.877084365454545

00:21:11.433 --> 00:21:13.737 found that many of the practitioners  
NOTE Confidence: 0.877084365454545

00:21:13.805 --> 00:21:15.821 felt they had to re allocate time  
NOTE Confidence: 0.877084365454545

00:21:15.821 --> 00:21:17.028 to address the misinformation,  
NOTE Confidence: 0.877084365454545

00:21:17.028 --> 00:21:18.718 and that that was something  
NOTE Confidence: 0.877084365454545

00:21:18.718 --> 00:21:20.070 they really worried about.  
NOTE Confidence: 0.877084365454545

00:21:20.070 --> 00:21:21.930 Turn that visits.  
NOTE Confidence: 0.923775001111111

00:21:21.930 --> 00:21:24.352 We worry that too much information will  
NOTE Confidence: 0.923775001111111

00:21:24.352 --> 00:21:26.586 overwhelm families, and many families  
NOTE Confidence: 0.923775001111111

00:21:26.586 --> 00:21:29.658 agreed that social media is overwhelming.  
NOTE Confidence: 0.923775001111111

00:21:29.660 --> 00:21:32.166 But pairings in at least one study  
NOTE Confidence: 0.923775001111111

00:21:32.166 --> 00:21:34.046 reported being very strongly advised  
NOTE Confidence: 0.923775001111111

00:21:34.046 --> 00:21:36.870 not to do so by physicians, with many,  
NOTE Confidence: 0.923775001111111

00:21:36.870 --> 00:21:38.760 many physicians telling them the information  
NOTE Confidence: 0.923775001111111

00:21:38.760 --> 00:21:40.746 will just scare you or overwhelm you.  
NOTE Confidence: 0.923775001111111

00:21:40.750 --> 00:21:42.706 Which, as I'll come back to,  
NOTE Confidence: 0.923775001111111

00:21:42.710 --> 00:21:45.216 doesn't leave them with the tools for

NOTE Confidence: 0.9237750011111111  
00:21:45.216 --> 00:21:47.412 how to navigate particularly conflicting  
NOTE Confidence: 0.9237750011111111  
00:21:47.412 --> 00:21:50.556 information when they come across it.  
NOTE Confidence: 0.9237750011111111  
00:21:50.560 --> 00:21:52.630 Well, we worry justly that parents  
NOTE Confidence: 0.9237750011111111  
00:21:52.630 --> 00:21:55.558 are sharing in a way that compromises  
NOTE Confidence: 0.9237750011111111  
00:21:55.558 --> 00:21:57.530 children's privacy and safety.  
NOTE Confidence: 0.9237750011111111  
00:21:57.530 --> 00:21:59.474 And this this came up in our ethical  
NOTE Confidence: 0.9237750011111111  
00:21:59.474 --> 00:22:01.028 issues when we asked about them,  
NOTE Confidence: 0.9237750011111111  
00:22:01.030 --> 00:22:03.022 but not nearly as much as I would  
NOTE Confidence: 0.9237750011111111  
00:22:03.022 --> 00:22:05.360 have expected, or maybe even hoped.  
NOTE Confidence: 0.9237750011111111  
00:22:05.360 --> 00:22:06.280 And finally,  
NOTE Confidence: 0.9237750011111111  
00:22:06.280 --> 00:22:08.592 I think the shift in power is uncomfortable  
NOTE Confidence: 0.9237750011111111  
00:22:08.592 --> 00:22:11.197 for us adult patients who felt their  
NOTE Confidence: 0.9237750011111111  
00:22:11.197 --> 00:22:13.162 physicians disapproved tended to avoid  
NOTE Confidence: 0.9237750011111111  
00:22:13.225 --> 00:22:15.540 disclosing their sources of information.  
NOTE Confidence: 0.9237750011111111  
00:22:15.540 --> 00:22:17.022 Saying, Oh my friend said instead  
NOTE Confidence: 0.9237750011111111

00:22:17.022 --> 00:22:18.965 of I found on social media and  
NOTE Confidence: 0.9237750011111111

00:22:18.965 --> 00:22:20.753 they tended to leave their visits.  
NOTE Confidence: 0.9237750011111111

00:22:20.760 --> 00:22:22.734 More dissatisfied and we haven't studied  
NOTE Confidence: 0.9237750011111111

00:22:22.734 --> 00:22:25.417 that in quite the same way in Pediatrics,  
NOTE Confidence: 0.9237750011111111

00:22:25.420 --> 00:22:27.238 but at least in our population,  
NOTE Confidence: 0.9237750011111111

00:22:27.240 --> 00:22:29.224 I'll come back to talking a little bit  
NOTE Confidence: 0.9237750011111111

00:22:29.224 --> 00:22:31.400 at the end about what led to greater  
NOTE Confidence: 0.9237750011111111

00:22:31.400 --> 00:22:33.370 trust or less trust and encounters,  
NOTE Confidence: 0.9237750011111111

00:22:33.370 --> 00:22:36.148 and people who felt judged definitely  
NOTE Confidence: 0.9237750011111111

00:22:36.148 --> 00:22:38.800 left their encounters less satisfied.  
NOTE Confidence: 0.9237750011111111

00:22:38.800 --> 00:22:41.368 But so there are four main ethical issues  
NOTE Confidence: 0.9237750011111111

00:22:41.368 --> 00:22:43.807 that come up that have been identified  
NOTE Confidence: 0.9237750011111111

00:22:43.807 --> 00:22:46.299 by researchers and then by the parents  
NOTE Confidence: 0.9237750011111111

00:22:46.299 --> 00:22:48.375 and the physicians in our study.  
NOTE Confidence: 0.9237750011111111

00:22:48.380 --> 00:22:49.540 And they're really a matter  
NOTE Confidence: 0.9237750011111111

00:22:49.540 --> 00:22:50.468 of scope and scale.

NOTE Confidence: 0.9237750011111111  
00:22:50.470 --> 00:22:52.140 None of these are completely  
NOTE Confidence: 0.9237750011111111  
00:22:52.140 --> 00:22:53.476 unique to social media.  
NOTE Confidence: 0.9237750011111111  
00:22:53.480 --> 00:22:55.420 It's just that social media  
NOTE Confidence: 0.9237750011111111  
00:22:55.420 --> 00:22:57.360 greatly changes the likelihood of  
NOTE Confidence: 0.9237750011111111  
00:22:57.424 --> 00:22:59.458 any of these becoming a problem.  
NOTE Confidence: 0.9237750011111111  
00:22:59.460 --> 00:23:01.806 And the extent to which they'll  
NOTE Confidence: 0.9237750011111111  
00:23:01.806 --> 00:23:02.979 become a problem.  
NOTE Confidence: 0.9237750011111111  
00:23:02.980 --> 00:23:06.196 Privacy is probably the biggest one,  
NOTE Confidence: 0.9237750011111111  
00:23:06.200 --> 00:23:07.682 or maybe one of the ones  
NOTE Confidence: 0.9237750011111111  
00:23:07.682 --> 00:23:09.250 that I worry about the most,  
NOTE Confidence: 0.9237750011111111  
00:23:09.250 --> 00:23:11.210 and the big questions here.  
NOTE Confidence: 0.9237750011111111  
00:23:11.210 --> 00:23:12.956 Who should get to decide whether  
NOTE Confidence: 0.9237750011111111  
00:23:12.956 --> 00:23:14.526 a minor patients health care  
NOTE Confidence: 0.9237750011111111  
00:23:14.526 --> 00:23:15.938 information is shared online?  
NOTE Confidence: 0.9237750011111111  
00:23:15.940 --> 00:23:17.550 Is this entirely at parents  
NOTE Confidence: 0.9237750011111111

00:23:17.550 --> 00:23:18.838 discretion and right now?  
NOTE Confidence: 0.9237750011111111

00:23:18.840 --> 00:23:19.161 Legally,  
NOTE Confidence: 0.9237750011111111

00:23:19.161 --> 00:23:21.729 it really is and and I have been  
NOTE Confidence: 0.9237750011111111

00:23:21.729 --> 00:23:24.172 maybe a little bit surprised that  
NOTE Confidence: 0.9237750011111111

00:23:24.172 --> 00:23:26.721 there aren't more adult children of  
NOTE Confidence: 0.9237750011111111

00:23:26.721 --> 00:23:29.295 oversharing parents pushing back on this.  
NOTE Confidence: 0.9237750011111111

00:23:29.300 --> 00:23:30.182 Although there is,  
NOTE Confidence: 0.9237750011111111

00:23:30.182 --> 00:23:31.946 I think some evidence that generations  
NOTE Confidence: 0.9237750011111111

00:23:31.946 --> 00:23:33.219 these shares a little bit.  
NOTE Confidence: 0.9237750011111111

00:23:33.220 --> 00:23:35.140 Let's so maybe that's in response  
NOTE Confidence: 0.9237750011111111

00:23:35.140 --> 00:23:36.420 to their parents sharing,  
NOTE Confidence: 0.9237750011111111

00:23:36.420 --> 00:23:38.226 but right now there's no legal  
NOTE Confidence: 0.9237750011111111

00:23:38.226 --> 00:23:39.798 protections for children with regard  
NOTE Confidence: 0.9237750011111111

00:23:39.798 --> 00:23:41.664 to what information their parents can  
NOTE Confidence: 0.9237750011111111

00:23:41.664 --> 00:23:43.558 post online about their health care.  
NOTE Confidence: 0.9237750011111111

00:23:43.560 --> 00:23:45.905 Even where we may suspect that there

NOTE Confidence: 0.9237750011111111  
00:23:45.905 --> 00:23:47.830 will be downstream consequences or  
NOTE Confidence: 0.9237750011111111  
00:23:47.830 --> 00:23:49.538 could be downstream consequences  
NOTE Confidence: 0.9237750011111111  
00:23:49.538 --> 00:23:51.490 when that child grows up.  
NOTE Confidence: 0.9237750011111111  
00:23:51.490 --> 00:23:53.245 Should health care professionals seek  
NOTE Confidence: 0.9237750011111111  
00:23:53.245 --> 00:23:55.380 additional information about a family online?  
NOTE Confidence: 0.9237750011111111  
00:23:55.380 --> 00:23:56.610 I tell my students no.  
NOTE Confidence: 0.9237750011111111  
00:23:56.610 --> 00:23:58.280 Please don't Google your families.  
NOTE Confidence: 0.9237750011111111  
00:23:58.280 --> 00:23:59.888 That's that's not if you were  
NOTE Confidence: 0.9237750011111111  
00:23:59.888 --> 00:24:00.960 invited into that space.  
NOTE Confidence: 0.9237750011111111  
00:24:00.960 --> 00:24:03.536 That is different and something we can.  
NOTE Confidence: 0.9237750011111111  
00:24:03.540 --> 00:24:05.437 Explore on a case by case basis.  
NOTE Confidence: 0.9237750011111111  
00:24:05.440 --> 00:24:08.620 Say when a parent asks you to follow A blog,  
NOTE Confidence: 0.9237750011111111  
00:24:08.620 --> 00:24:10.870 but otherwise we should not be  
NOTE Confidence: 0.9237750011111111  
00:24:10.870 --> 00:24:13.240 out there looking for information  
NOTE Confidence: 0.9237750011111111  
00:24:13.240 --> 00:24:15.298 and then how do we respond when  
NOTE Confidence: 0.9237750011111111

00:24:15.298 --> 00:24:16.180 patients or families  
NOTE Confidence: 0.921328332857143

00:24:16.237 --> 00:24:17.987 seek information about us online  
NOTE Confidence: 0.921328332857143

00:24:17.987 --> 00:24:20.048 or have found something about us  
NOTE Confidence: 0.921328332857143

00:24:20.048 --> 00:24:21.777 online and want to ask about it?  
NOTE Confidence: 0.921328332857143

00:24:21.780 --> 00:24:25.086 Uhm, confidentiality shows up a lot,  
NOTE Confidence: 0.921328332857143

00:24:25.090 --> 00:24:27.370 particularly with certain conditions and  
NOTE Confidence: 0.921328332857143

00:24:27.370 --> 00:24:30.327 and centers where families all know each  
NOTE Confidence: 0.921328332857143

00:24:30.327 --> 00:24:32.743 other and are both on social media as  
NOTE Confidence: 0.921328332857143

00:24:32.812 --> 00:24:35.444 well as being treated at the same center.  
NOTE Confidence: 0.921328332857143

00:24:35.450 --> 00:24:37.943 And this is one of those issues that that  
NOTE Confidence: 0.921328332857143

00:24:37.943 --> 00:24:40.371 could have happened at any time with  
NOTE Confidence: 0.921328332857143

00:24:40.371 --> 00:24:42.650 conversations in kitchens or waiting rooms,  
NOTE Confidence: 0.921328332857143

00:24:42.650 --> 00:24:44.449 but it's just so much more likely  
NOTE Confidence: 0.921328332857143

00:24:44.449 --> 00:24:46.287 to happen when families are on  
NOTE Confidence: 0.921328332857143

00:24:46.287 --> 00:24:48.309 social media because they can share  
NOTE Confidence: 0.921328332857143

00:24:48.309 --> 00:24:49.829 information so much more readily,

NOTE Confidence: 0.921328332857143

00:24:49.830 --> 00:24:51.378 and that there's a sense of.

NOTE Confidence: 0.921328332857143

00:24:51.380 --> 00:24:53.190 Anonymity that often takes people

NOTE Confidence: 0.921328332857143

00:24:53.190 --> 00:24:55.470 some barriers down that takes people,

NOTE Confidence: 0.921328332857143

00:24:55.470 --> 00:24:57.850 take their guards down a little bit,

NOTE Confidence: 0.921328332857143

00:24:57.850 --> 00:25:00.034 so we have to really carefully navigate

NOTE Confidence: 0.921328332857143

00:25:00.034 --> 00:25:02.560 when a family is questioned to us is

NOTE Confidence: 0.921328332857143

00:25:02.560 --> 00:25:04.574 really rooted in what they've heard

NOTE Confidence: 0.921328332857143

00:25:04.574 --> 00:25:07.088 about someone else's treatments and make

NOTE Confidence: 0.921328332857143

00:25:07.088 --> 00:25:09.542 sure that we're not inadvertently violating

NOTE Confidence: 0.921328332857143

00:25:09.542 --> 00:25:12.079 the other patients confidentiality.

NOTE Confidence: 0.921328332857143

00:25:12.080 --> 00:25:14.060 I was incredibly impressed that the

NOTE Confidence: 0.921328332857143

00:25:14.060 --> 00:25:16.371 parents in our study independently and

NOTE Confidence: 0.921328332857143

00:25:16.371 --> 00:25:19.155 spontaneously identified equity as a concern.

NOTE Confidence: 0.921328332857143

00:25:19.160 --> 00:25:20.222 On one side,

NOTE Confidence: 0.921328332857143

00:25:20.222 --> 00:25:22.346 we have the resource allocation question.

NOTE Confidence: 0.921328332857143

00:25:22.350 --> 00:25:24.734 We have a limited amount of time as  
NOTE Confidence: 0.921328332857143

00:25:24.734 --> 00:25:26.380 clinicians. How do we balance visit?  
NOTE Confidence: 0.921328332857143

00:25:26.380 --> 00:25:28.165 Priority is when we may have one  
NOTE Confidence: 0.921328332857143

00:25:28.165 --> 00:25:30.321 set of goals for a visit and the  
NOTE Confidence: 0.921328332857143

00:25:30.321 --> 00:25:32.169 family may have another set involving  
NOTE Confidence: 0.921328332857143

00:25:32.169 --> 00:25:34.439 recommendations found on social media,  
NOTE Confidence: 0.921328332857143

00:25:34.440 --> 00:25:36.392 or it may just become clear to us  
NOTE Confidence: 0.921328332857143

00:25:36.392 --> 00:25:38.452 that they really need some education  
NOTE Confidence: 0.921328332857143

00:25:38.452 --> 00:25:40.342 regarding their social media use.  
NOTE Confidence: 0.921328332857143

00:25:40.350 --> 00:25:42.044 And then this question of the social  
NOTE Confidence: 0.921328332857143

00:25:42.044 --> 00:25:43.329 media really leveled the playing.  
NOTE Confidence: 0.921328332857143

00:25:43.330 --> 00:25:45.826 Field or does it just exacerbate  
NOTE Confidence: 0.921328332857143

00:25:45.826 --> 00:25:46.658 existing disparities?  
NOTE Confidence: 0.921328332857143

00:25:46.660 --> 00:25:49.138 Several of the parents in our study  
NOTE Confidence: 0.921328332857143

00:25:49.138 --> 00:25:50.959 described concerns that social media  
NOTE Confidence: 0.921328332857143

00:25:50.959 --> 00:25:53.047 just makes it easier for already

NOTE Confidence: 0.921328332857143

00:25:53.047 --> 00:25:54.797 educated and well connected people

NOTE Confidence: 0.921328332857143

00:25:54.797 --> 00:25:57.107 to be even more educated and well

NOTE Confidence: 0.921328332857143

00:25:57.110 --> 00:25:58.690 connected rather than actually.

NOTE Confidence: 0.921328332857143

00:25:58.690 --> 00:26:03.760 As I said earlier, democratizing information.

NOTE Confidence: 0.921328332857143

00:26:03.760 --> 00:26:05.260 And finally, treatment disagreements.

NOTE Confidence: 0.921328332857143

00:26:05.260 --> 00:26:08.237 And this is where all focus for the

NOTE Confidence: 0.921328332857143

00:26:08.237 --> 00:26:09.887 second half of the presentation.

NOTE Confidence: 0.921328332857143

00:26:09.890 --> 00:26:11.500 So refusal of recommended treatment

NOTE Confidence: 0.921328332857143

00:26:11.500 --> 00:26:13.572 and or requests for non recommended

NOTE Confidence: 0.921328332857143

00:26:13.572 --> 00:26:15.188 treatment and particularly where

NOTE Confidence: 0.921328332857143

00:26:15.188 --> 00:26:17.208 social media comes into play.

NOTE Confidence: 0.921328332857143

00:26:17.210 --> 00:26:19.779 These often overlap that family is are

NOTE Confidence: 0.921328332857143

00:26:19.779 --> 00:26:21.345 refusing something because something

NOTE Confidence: 0.921328332857143

00:26:21.345 --> 00:26:23.370 else has been recommended online,

NOTE Confidence: 0.921328332857143

00:26:23.370 --> 00:26:25.580 not what their physician recommended.

NOTE Confidence: 0.921328332857143

00:26:25.580 --> 00:26:28.364 This is certainly not unique to social media,  
NOTE Confidence: 0.921328332857143

00:26:28.370 --> 00:26:31.121 but social media is very much a  
NOTE Confidence: 0.921328332857143

00:26:31.121 --> 00:26:33.490 catalyst for these disagreements.  
NOTE Confidence: 0.921328332857143

00:26:33.490 --> 00:26:36.402 And there's really three ways in which  
NOTE Confidence: 0.921328332857143

00:26:36.402 --> 00:26:38.819 social media catalyzes these conflicts.  
NOTE Confidence: 0.921328332857143

00:26:38.820 --> 00:26:40.746 The first is as an instigator  
NOTE Confidence: 0.921328332857143

00:26:40.746 --> 00:26:41.709 of the conflict.  
NOTE Confidence: 0.921328332857143

00:26:41.710 --> 00:26:44.068 So when families come across conflicting  
NOTE Confidence: 0.921328332857143

00:26:44.068 --> 00:26:46.337 information on social media or read  
NOTE Confidence: 0.921328332857143

00:26:46.337 --> 00:26:48.245 something on social media and then  
NOTE Confidence: 0.921328332857143

00:26:48.245 --> 00:26:50.480 their doctor or other health care  
NOTE Confidence: 0.921328332857143

00:26:50.480 --> 00:26:52.405 provider says something very different.  
NOTE Confidence: 0.921328332857143

00:26:52.410 --> 00:26:54.755 It can be an uncover of conflict.  
NOTE Confidence: 0.921328332857143

00:26:54.760 --> 00:26:55.350 When we,  
NOTE Confidence: 0.921328332857143

00:26:55.350 --> 00:26:57.710 when we do realize what families are doing,  
NOTE Confidence: 0.921328332857143

00:26:57.710 --> 00:27:00.650 their social media activities and those

NOTE Confidence: 0.921328332857143  
00:27:00.650 --> 00:27:02.610 reveal ethically concerning behavior.  
NOTE Confidence: 0.921328332857143  
00:27:02.610 --> 00:27:03.918 And finally it can be in.  
NOTE Confidence: 0.921328332857143  
00:27:03.920 --> 00:27:05.198 Accelerator of conflict.  
NOTE Confidence: 0.921328332857143  
00:27:05.198 --> 00:27:07.754 When a pre-existing disagreement goes viral,  
NOTE Confidence: 0.921328332857143  
00:27:07.760 --> 00:27:09.940 either intentionally or unintentionally,  
NOTE Confidence: 0.921328332857143  
00:27:09.940 --> 00:27:13.210 on the part of the family.  
NOTE Confidence: 0.921328332857143  
00:27:13.210 --> 00:27:14.860 Social media is an instigator.  
NOTE Confidence: 0.921328332857143  
00:27:14.860 --> 00:27:17.016 These are all examples from our study.  
NOTE Confidence: 0.921328332857143  
00:27:17.020 --> 00:27:18.348 So in one case,  
NOTE Confidence: 0.921328332857143  
00:27:18.348 --> 00:27:20.340 a parent described being questioned pretty  
NOTE Confidence: 0.91971497  
00:27:20.398 --> 00:27:22.162 aggressively by other parents  
NOTE Confidence: 0.91971497  
00:27:22.162 --> 00:27:23.485 regarding her daughters,  
NOTE Confidence: 0.91971497  
00:27:23.490 --> 00:27:26.604 physicians decision to monitor for recurrence  
NOTE Confidence: 0.91971497  
00:27:26.604 --> 00:27:29.469 with ultrasound rather than CT or MRI.  
NOTE Confidence: 0.91971497  
00:27:29.470 --> 00:27:32.039 And although we had physician parent dyads,  
NOTE Confidence: 0.91971497

00:27:32.040 --> 00:27:34.518 most of the physicians did not recall  
NOTE Confidence: 0.91971497

00:27:34.518 --> 00:27:36.035 specific incidents of conflicting  
NOTE Confidence: 0.91971497

00:27:36.035 --> 00:27:38.765 information in the way that parents did.  
NOTE Confidence: 0.91971497

00:27:38.770 --> 00:27:41.020 So the only the only side of the information  
NOTE Confidence: 0.91971497

00:27:41.020 --> 00:27:43.017 I really have is the parent side.  
NOTE Confidence: 0.91971497

00:27:43.020 --> 00:27:44.790 But her her impression from this  
NOTE Confidence: 0.91971497

00:27:44.790 --> 00:27:46.532 encounter was that her center was  
NOTE Confidence: 0.91971497

00:27:46.532 --> 00:27:48.296 practicing in a more out of date  
NOTE Confidence: 0.91971497

00:27:48.296 --> 00:27:50.634 way or was not using the most  
NOTE Confidence: 0.91971497

00:27:50.634 --> 00:27:51.986 up-to-date evidence based guidelines.  
NOTE Confidence: 0.91971497

00:27:51.990 --> 00:27:53.606 Another parent reported learning  
NOTE Confidence: 0.91971497

00:27:53.606 --> 00:27:55.222 that radiation was sometimes  
NOTE Confidence: 0.91971497

00:27:55.222 --> 00:27:56.800 effective for her child's disease,  
NOTE Confidence: 0.91971497

00:27:56.800 --> 00:27:58.175 according to other parents of  
NOTE Confidence: 0.91971497

00:27:58.175 --> 00:27:59.610 children with the same disease.  
NOTE Confidence: 0.91971497

00:27:59.610 --> 00:28:01.388 Although she thought her oncologist had said,

NOTE Confidence: 0.91971497

00:28:01.390 --> 00:28:03.966 but it never worked in this parent described,

NOTE Confidence: 0.91971497

00:28:03.970 --> 00:28:06.610 never getting a satisfactory resolution

NOTE Confidence: 0.91971497

00:28:06.610 --> 00:28:08.722 on that conflicting information,

NOTE Confidence: 0.91971497

00:28:08.730 --> 00:28:10.040 and then another parent described

NOTE Confidence: 0.91971497

00:28:10.040 --> 00:28:11.869 belonging to a group where they all

NOTE Confidence: 0.91971497

00:28:11.869 --> 00:28:13.279 got together and talked about the.

NOTE Confidence: 0.91971497

00:28:13.280 --> 00:28:15.164 Variation between their programs

NOTE Confidence: 0.91971497

00:28:15.164 --> 00:28:17.048 and advice regarding restrictions

NOTE Confidence: 0.91971497

00:28:17.048 --> 00:28:19.280 related to everyday life which.

NOTE Confidence: 0.91971497

00:28:19.280 --> 00:28:20.561 For any of you who are oncologists

NOTE Confidence: 0.91971497

00:28:20.561 --> 00:28:21.519 in the audience will know,

NOTE Confidence: 0.91971497

00:28:21.520 --> 00:28:23.392 there is a lot of variation and some

NOTE Confidence: 0.91971497

00:28:23.392 --> 00:28:25.008 programs are much more conservative.

NOTE Confidence: 0.91971497

00:28:25.010 --> 00:28:26.780 Others are much more relaxed.

NOTE Confidence: 0.91971497

00:28:26.780 --> 00:28:28.324 That's not necessarily something

NOTE Confidence: 0.91971497

00:28:28.324 --> 00:28:29.868 we disclose to parents,  
NOTE Confidence: 0.91971497

00:28:29.870 --> 00:28:32.054 or that parents realize until they start  
NOTE Confidence: 0.91971497

00:28:32.054 --> 00:28:34.400 talking to people treated at other centers,  
NOTE Confidence: 0.91971497

00:28:34.400 --> 00:28:37.508 and all of those were the instigators  
NOTE Confidence: 0.91971497

00:28:37.508 --> 00:28:40.320 of conflict with their physicians.  
NOTE Confidence: 0.91971497

00:28:40.320 --> 00:28:42.224 So this is a quote from one of  
NOTE Confidence: 0.91971497

00:28:42.224 --> 00:28:43.259 our participants who wrote.  
NOTE Confidence: 0.91971497

00:28:43.260 --> 00:28:44.970 There are tons of treatment options  
NOTE Confidence: 0.91971497

00:28:44.970 --> 00:28:47.034 that are and never will be presented  
NOTE Confidence: 0.91971497

00:28:47.034 --> 00:28:49.064 by my physician and she she described  
NOTE Confidence: 0.91971497

00:28:49.120 --> 00:28:50.968 it as being very frustrating that she  
NOTE Confidence: 0.91971497

00:28:50.968 --> 00:28:53.160 had to spend hours on Facebook to find  
NOTE Confidence: 0.91971497

00:28:53.160 --> 00:28:55.110 the most fitting treatment for her child.  
NOTE Confidence: 0.91971497

00:28:55.110 --> 00:28:56.485 When she's not the one  
NOTE Confidence: 0.91971497

00:28:56.485 --> 00:28:57.585 with the medical license.  
NOTE Confidence: 0.91971497

00:28:57.590 --> 00:28:59.958 And I think this really speaks to the

NOTE Confidence: 0.91971497

00:28:59.958 --> 00:29:02.021 way in which social media applies

NOTE Confidence: 0.91971497

00:29:02.021 --> 00:29:04.528 a new form of pressure to parents

NOTE Confidence: 0.91971497

00:29:04.528 --> 00:29:06.880 who have always in in many venues

NOTE Confidence: 0.91971497

00:29:06.880 --> 00:29:08.378 and many settings sometimes.

NOTE Confidence: 0.91971497

00:29:08.378 --> 00:29:11.650 Felt like doing the best for their child

NOTE Confidence: 0.91971497

00:29:11.720 --> 00:29:14.380 means making sure no stone is unturned.

NOTE Confidence: 0.91971497

00:29:14.380 --> 00:29:16.300 With social media there are millions

NOTE Confidence: 0.91971497

00:29:16.300 --> 00:29:18.731 of more stones to turn over than ever

NOTE Confidence: 0.91971497

00:29:18.731 --> 00:29:20.786 before and that's a lot of additional

NOTE Confidence: 0.91971497

00:29:20.786 --> 00:29:23.271 stress for families as well As for

NOTE Confidence: 0.91971497

00:29:23.271 --> 00:29:25.175 physicians and health care providers

NOTE Confidence: 0.91971497

00:29:25.175 --> 00:29:28.382 who feel like they have to respond to

NOTE Confidence: 0.91971497

00:29:28.382 --> 00:29:30.614 every stone the family turns over.

NOTE Confidence: 0.91971497

00:29:30.620 --> 00:29:31.784 In our study,

NOTE Confidence: 0.91971497

00:29:31.784 --> 00:29:33.716 so 70% of our study participants.

NOTE Confidence: 0.91971497

00:29:33.716 --> 00:29:35.161 That's the ninety who completed  
NOTE Confidence: 0.91971497

00:29:35.161 --> 00:29:36.160 the questionnaire,  
NOTE Confidence: 0.91971497

00:29:36.160 --> 00:29:38.095 reported that they'd experienced a  
NOTE Confidence: 0.91971497

00:29:38.095 --> 00:29:40.030 situation in which information on  
NOTE Confidence: 0.91971497

00:29:40.087 --> 00:29:42.297 social media conflicted with information  
NOTE Confidence: 0.91971497

00:29:42.297 --> 00:29:44.065 provided by their oncologist.  
NOTE Confidence: 0.91971497

00:29:44.070 --> 00:29:47.136 And again, this is the parents experience,  
NOTE Confidence: 0.91971497

00:29:47.140 --> 00:29:48.502 but I actually think that's what's  
NOTE Confidence: 0.91971497

00:29:48.502 --> 00:29:48.956 most important.  
NOTE Confidence: 0.91971497

00:29:48.960 --> 00:29:49.206 I,  
NOTE Confidence: 0.91971497

00:29:49.206 --> 00:29:50.928 I think the important part is that  
NOTE Confidence: 0.91971497

00:29:50.928 --> 00:29:52.879 the the parent felt the conflict  
NOTE Confidence: 0.91971497

00:29:52.879 --> 00:29:54.275 and saw the disagreements,  
NOTE Confidence: 0.91971497

00:29:54.280 --> 00:29:57.028 not whether or not the information  
NOTE Confidence: 0.91971497

00:29:57.028 --> 00:29:59.750 provided in clinic actually conflicted.  
NOTE Confidence: 0.91971497

00:29:59.750 --> 00:30:01.635 And these involved everything from

NOTE Confidence: 0.91971497

00:30:01.635 --> 00:30:04.170 diagnosis all the way through treatment,

NOTE Confidence: 0.91971497

00:30:04.170 --> 00:30:05.970 adverse effects, quality of life,

NOTE Confidence: 0.91971497

00:30:05.970 --> 00:30:07.250 and complementary and alternative

NOTE Confidence: 0.91971497

00:30:07.250 --> 00:30:11.000 medicine was a big one, unsurprisingly.

NOTE Confidence: 0.91971497

00:30:11.000 --> 00:30:12.380 Another parent wrote every time

NOTE Confidence: 0.91971497

00:30:12.380 --> 00:30:13.484 I have a concern.

NOTE Confidence: 0.903371527826087

00:30:13.490 --> 00:30:15.142 I Google or use social media of

NOTE Confidence: 0.903371527826087

00:30:15.142 --> 00:30:16.910 some kind to educate myself on

NOTE Confidence: 0.903371527826087

00:30:16.910 --> 00:30:18.575 what others experience and then

NOTE Confidence: 0.903371527826087

00:30:18.575 --> 00:30:20.160 question our team of doctors.

NOTE Confidence: 0.903371527826087

00:30:20.160 --> 00:30:22.836 Never do the two answers match.

NOTE Confidence: 0.903371527826087

00:30:22.840 --> 00:30:24.350 I'm not surprised by this.

NOTE Confidence: 0.903371527826087

00:30:24.350 --> 00:30:26.606 This was very much my experience

NOTE Confidence: 0.903371527826087

00:30:26.606 --> 00:30:28.110 as a junior physician.

NOTE Confidence: 0.903371527826087

00:30:28.110 --> 00:30:29.940 Whenever I asked a question that

NOTE Confidence: 0.903371527826087

00:30:29.940 --> 00:30:31.503 wasn't something that would normally  
NOTE Confidence: 0.903371527826087

00:30:31.503 --> 00:30:33.533 get studied in a clinical trial or  
NOTE Confidence: 0.903371527826087

00:30:33.533 --> 00:30:35.129 have rigorous evidence behind it.  
NOTE Confidence: 0.903371527826087

00:30:35.130 --> 00:30:36.800 It's it's just so common,  
NOTE Confidence: 0.903371527826087

00:30:36.800 --> 00:30:38.823 I think much more common than parents  
NOTE Confidence: 0.903371527826087

00:30:38.823 --> 00:30:40.680 realize until they're deeply immersed in.  
NOTE Confidence: 0.903371527826087

00:30:40.680 --> 00:30:42.381 Health care that we don't have all  
NOTE Confidence: 0.903371527826087

00:30:42.381 --> 00:30:44.031 the answers and that we're doing the  
NOTE Confidence: 0.903371527826087

00:30:44.031 --> 00:30:45.930 best we can based on our experience,  
NOTE Confidence: 0.903371527826087

00:30:45.930 --> 00:30:48.065 but the answers may not align even  
NOTE Confidence: 0.903371527826087

00:30:48.065 --> 00:30:49.970 between two providers on the same team.  
NOTE Confidence: 0.86912934125

00:30:52.900 --> 00:30:54.575 Another parent wrote the interactions  
NOTE Confidence: 0.86912934125

00:30:54.575 --> 00:30:56.603 of Facebook or hope when doctors  
NOTE Confidence: 0.86912934125

00:30:56.603 --> 00:30:58.088 say she's out of options.  
NOTE Confidence: 0.86912934125

00:30:58.090 --> 00:31:01.107 Facebook says try this. Will it work?  
NOTE Confidence: 0.86912934125

00:31:01.110 --> 00:31:03.756 TBD, but it's hope when our medical

NOTE Confidence: 0.86912934125

00:31:03.756 --> 00:31:05.480 team continually gives us none.

NOTE Confidence: 0.86912934125

00:31:05.480 --> 00:31:09.144 This could turn out to save her life.

NOTE Confidence: 0.86912934125

00:31:09.150 --> 00:31:11.328 And although part of me is troubled by this,

NOTE Confidence: 0.86912934125

00:31:11.330 --> 00:31:14.026 I also I think this is a really

NOTE Confidence: 0.86912934125

00:31:14.026 --> 00:31:16.129 important view for us to recognize

NOTE Confidence: 0.86912934125

00:31:16.129 --> 00:31:18.600 and and be willing to work with.

NOTE Confidence: 0.86912934125

00:31:18.600 --> 00:31:20.176 On the flip side,

NOTE Confidence: 0.86912934125

00:31:20.176 --> 00:31:23.282 we had some families who had experienced

NOTE Confidence: 0.86912934125

00:31:23.282 --> 00:31:26.612 almost a harassment online with many

NOTE Confidence: 0.86912934125

00:31:26.612 --> 00:31:28.417 people in their circles challenging

NOTE Confidence: 0.86912934125

00:31:28.417 --> 00:31:30.499 their decisions to use traditional

NOTE Confidence: 0.86912934125

00:31:30.499 --> 00:31:32.839 chemotherapy to use conventional medicine,

NOTE Confidence: 0.86912934125

00:31:32.840 --> 00:31:34.525 and saying that you're actually

NOTE Confidence: 0.86912934125

00:31:34.525 --> 00:31:36.210 killing him by doing this.

NOTE Confidence: 0.86912934125

00:31:36.210 --> 00:31:38.217 And, and this is for at least some family

NOTE Confidence: 0.86912934125

00:31:38.217 --> 00:31:40.194 is going to be the start of planting  
NOTE Confidence: 0.86912934125

00:31:40.194 --> 00:31:42.399 that seed that maybe we're not doing the  
NOTE Confidence: 0.86912934125

00:31:42.399 --> 00:31:44.758 right thing by seeking Western medical care.  
NOTE Confidence: 0.86912934125

00:31:44.758 --> 00:31:46.634 Maybe these oncologists don't  
NOTE Confidence: 0.86912934125

00:31:46.634 --> 00:31:48.510 know what they're doing.  
NOTE Confidence: 0.86912934125

00:31:48.510 --> 00:31:49.776 A social media,  
NOTE Confidence: 0.86912934125

00:31:49.776 --> 00:31:51.886 as an uncover of conflict.  
NOTE Confidence: 0.86912934125

00:31:51.890 --> 00:31:54.648 So I have actually three different scenarios,  
NOTE Confidence: 0.86912934125

00:31:54.650 --> 00:31:56.866 both from our study and from our hospital  
NOTE Confidence: 0.86912934125

00:31:56.866 --> 00:31:58.847 that I think are pretty representative  
NOTE Confidence: 0.86912934125

00:31:58.847 --> 00:32:01.307 of the ways in which social media  
NOTE Confidence: 0.86912934125

00:32:01.307 --> 00:32:03.087 can uncover or reveal conflict,  
NOTE Confidence: 0.86912934125

00:32:03.090 --> 00:32:04.430 rather than instigating it.  
NOTE Confidence: 0.86912934125

00:32:04.430 --> 00:32:06.440 This one from our hospital would  
NOTE Confidence: 0.86912934125

00:32:06.502 --> 00:32:08.680 involve the patient who was receiving  
NOTE Confidence: 0.86912934125

00:32:08.680 --> 00:32:10.530 experimental therapy out of state,

NOTE Confidence: 0.86912934125

00:32:10.530 --> 00:32:12.820 and her parents had set up a go fund me

NOTE Confidence: 0.86912934125

00:32:12.880 --> 00:32:15.057 page seeking funds to pay for treatment

NOTE Confidence: 0.86912934125

00:32:15.057 --> 00:32:17.170 when the team learned about this,

NOTE Confidence: 0.86912934125

00:32:17.170 --> 00:32:18.650 they became very concerned that.

NOTE Confidence: 0.86912934125

00:32:18.650 --> 00:32:20.205 Her parents were being dishonest

NOTE Confidence: 0.86912934125

00:32:20.205 --> 00:32:22.176 with their friends and donors about

NOTE Confidence: 0.86912934125

00:32:22.176 --> 00:32:23.604 their financial situation because

NOTE Confidence: 0.86912934125

00:32:23.604 --> 00:32:25.389 they had good health insurance.

NOTE Confidence: 0.86912934125

00:32:25.390 --> 00:32:27.420 The experimental therapy was not

NOTE Confidence: 0.86912934125

00:32:27.420 --> 00:32:30.036 at any cost and we had connected

NOTE Confidence: 0.86912934125

00:32:30.036 --> 00:32:31.781 them with several different sources

NOTE Confidence: 0.86912934125

00:32:31.781 --> 00:32:34.042 of financial assistance for any

NOTE Confidence: 0.86912934125

00:32:34.042 --> 00:32:36.378 uncovered expenses and in many ways

NOTE Confidence: 0.86912934125

00:32:36.378 --> 00:32:38.490 this is mostly about the staff's

NOTE Confidence: 0.86912934125

00:32:38.569 --> 00:32:40.777 moral distress at having to sit

NOTE Confidence: 0.86912934125

00:32:40.777 --> 00:32:43.515 with this legally and and I think  
NOTE Confidence: 0.86912934125

00:32:43.515 --> 00:32:45.510 ethically in terms of confidentiality.  
NOTE Confidence: 0.86912934125

00:32:45.510 --> 00:32:46.960 There wasn't really an appropriate  
NOTE Confidence: 0.86912934125

00:32:46.960 --> 00:32:48.930 recourse for us to do anything.  
NOTE Confidence: 0.86912934125

00:32:48.930 --> 00:32:50.952 About this and we didn't necessarily  
NOTE Confidence: 0.86912934125

00:32:50.952 --> 00:32:51.963 know everything either.  
NOTE Confidence: 0.86912934125

00:32:51.970 --> 00:32:54.250 There may where there may very well have  
NOTE Confidence: 0.86912934125

00:32:54.250 --> 00:32:56.168 been pieces of this family's financial  
NOTE Confidence: 0.86912934125

00:32:56.168 --> 00:32:58.106 story that we didn't know about,  
NOTE Confidence: 0.86912934125

00:32:58.110 --> 00:33:00.334 and I think there was also some concern  
NOTE Confidence: 0.86912934125

00:33:00.334 --> 00:33:02.127 that this was making the hospital  
NOTE Confidence: 0.86912934125

00:33:02.127 --> 00:33:04.313 look bad when we were trying to  
NOTE Confidence: 0.86912934125

00:33:04.313 --> 00:33:06.108 provide assistance for this family.  
NOTE Confidence: 0.86912934125

00:33:06.110 --> 00:33:08.819 So that was one source of of  
NOTE Confidence: 0.86912934125

00:33:08.819 --> 00:33:10.790 ethical concern and distress.  
NOTE Confidence: 0.86912934125

00:33:10.790 --> 00:33:11.489 The second one,

NOTE Confidence: 0.86912934125

00:33:11.489 --> 00:33:13.497 and this has come up a lot in

NOTE Confidence: 0.86912934125

00:33:13.497 --> 00:33:15.102 different settings lately and I

NOTE Confidence: 0.86912934125

00:33:15.102 --> 00:33:16.977 heard someone else talk about a

NOTE Confidence: 0.86912934125

00:33:16.977 --> 00:33:18.555 similar case at CBH last week.

NOTE Confidence: 0.86912934125

00:33:18.560 --> 00:33:20.432 Involved a teenager who was admitted

NOTE Confidence: 0.86912934125

00:33:20.432 --> 00:33:22.719 to the ICU and the team discovered

NOTE Confidence: 0.86912934125

00:33:22.719 --> 00:33:24.987 that his mom had started a really

NOTE Confidence: 0.86912934125

00:33:25.057 --> 00:33:27.703 detailed and nuanced blog about his

NOTE Confidence: 0.86912934125

00:33:27.703 --> 00:33:29.467 condition that included photographs,

NOTE Confidence: 0.86912934125

00:33:29.470 --> 00:33:30.802 and particularly regardless

NOTE Confidence: 0.86912934125

00:33:30.802 --> 00:33:32.422 of the child's age.

NOTE Confidence: 0.86912934125

00:33:32.422 --> 00:33:34.252 I think there are appropriate

NOTE Confidence: 0.86912934125

00:33:34.252 --> 00:33:36.370 concerns about the child's privacy,

NOTE Confidence: 0.86912934125

00:33:36.370 --> 00:33:38.386 about the dignity of the child,

NOTE Confidence: 0.86912934125

00:33:38.390 --> 00:33:39.502 and potentially about what

NOTE Confidence: 0.86912934125

00:33:39.502 --> 00:33:40.892 are the implications of this.  
NOTE Confidence: 0.86912934125

00:33:40.900 --> 00:33:42.741 10 or 20 years down the road  
NOTE Confidence: 0.86912934125

00:33:42.741 --> 00:33:43.860 when someone googles them,  
NOTE Confidence: 0.86912934125

00:33:43.860 --> 00:33:44.988 could they find this,  
NOTE Confidence: 0.86912934125

00:33:44.988 --> 00:33:46.680 but given his age it was  
NOTE Confidence: 0.922286524333334

00:33:46.745 --> 00:33:49.025 an especially urgent concern because he  
NOTE Confidence: 0.922286524333334

00:33:49.025 --> 00:33:51.512 wasn't a newborn where this might only  
NOTE Confidence: 0.922286524333334

00:33:51.512 --> 00:33:53.855 come back to be important to them in  
NOTE Confidence: 0.922286524333334

00:33:53.855 --> 00:33:55.970 15 or 20 years he was a teenager who  
NOTE Confidence: 0.922286524333334

00:33:56.039 --> 00:33:58.123 was applying to college and and would  
NOTE Confidence: 0.922286524333334

00:33:58.123 --> 00:33:59.740 be very likely to be in situations  
NOTE Confidence: 0.922286524333334

00:33:59.793 --> 00:34:01.480 where people who know him might find  
NOTE Confidence: 0.922286524333334

00:34:01.480 --> 00:34:03.157 this or might read about this and  
NOTE Confidence: 0.922286524333334

00:34:03.157 --> 00:34:05.340 might see him in a position that he  
NOTE Confidence: 0.922286524333334

00:34:05.340 --> 00:34:06.980 wasn't really uncomfortable with.  
NOTE Confidence: 0.922286524333334

00:34:06.980 --> 00:34:09.620 At the same time his mom, like a lot of

NOTE Confidence: 0.922286524333334

00:34:09.620 --> 00:34:11.290 parents in this situation felt like this.

NOTE Confidence: 0.922286524333334

00:34:11.290 --> 00:34:12.630 Was a really important source

NOTE Confidence: 0.922286524333334

00:34:12.630 --> 00:34:13.702 of support for her.

NOTE Confidence: 0.922286524333334

00:34:13.710 --> 00:34:16.257 This was a way of channeling her feelings of

NOTE Confidence: 0.922286524333334

00:34:16.257 --> 00:34:18.389 feeling more empowered and less helpless.

NOTE Confidence: 0.922286524333334

00:34:18.390 --> 00:34:20.814 It was a way of connecting

NOTE Confidence: 0.922286524333334

00:34:20.814 --> 00:34:22.430 and updating other people.

NOTE Confidence: 0.922286524333334

00:34:22.430 --> 00:34:23.984 And yes, there are lots of ways

NOTE Confidence: 0.922286524333334

00:34:23.984 --> 00:34:25.949 to do this that would be perhaps

NOTE Confidence: 0.922286524333334

00:34:25.949 --> 00:34:27.504 less public and more protected,

NOTE Confidence: 0.922286524333334

00:34:27.510 --> 00:34:29.274 and that I'll come back in the

NOTE Confidence: 0.922286524333334

00:34:29.274 --> 00:34:30.954 recommendations is part of the reason we

NOTE Confidence: 0.922286524333334

00:34:30.954 --> 00:34:32.740 need to do more education with families.

NOTE Confidence: 0.890525533

00:34:35.310 --> 00:34:37.020 Couple more quotes from our

NOTE Confidence: 0.890525533

00:34:37.020 --> 00:34:38.730 study so another family wrote,

NOTE Confidence: 0.890525533

00:34:38.730 --> 00:34:40.610 I think once you post anything on there,  
NOTE Confidence: 0.890525533

00:34:40.610 --> 00:34:41.770 you have to understand the  
NOTE Confidence: 0.890525533

00:34:41.770 --> 00:34:42.930 fact that it's out there.  
NOTE Confidence: 0.890525533

00:34:42.930 --> 00:34:44.666 People can find that people can read it.  
NOTE Confidence: 0.890525533

00:34:44.670 --> 00:34:46.006 So if you don't want something out there,  
NOTE Confidence: 0.890525533

00:34:46.010 --> 00:34:48.206 don't post it about your child.  
NOTE Confidence: 0.890525533

00:34:48.210 --> 00:34:49.254 A different parent wrote.  
NOTE Confidence: 0.890525533

00:34:49.254 --> 00:34:51.148 I made the decision when I started  
NOTE Confidence: 0.890525533

00:34:51.148 --> 00:34:53.080 writing and sharing online and all of  
NOTE Confidence: 0.890525533

00:34:53.080 --> 00:34:55.140 that that we were kind of an open book.  
NOTE Confidence: 0.890525533

00:34:55.140 --> 00:34:56.688 And for all of these parents,  
NOTE Confidence: 0.890525533

00:34:56.690 --> 00:34:57.910 when we interviewed them,  
NOTE Confidence: 0.890525533

00:34:57.910 --> 00:35:00.128 we probed a little more because these  
NOTE Confidence: 0.890525533

00:35:00.128 --> 00:35:02.120 are pretty reflective of the general  
NOTE Confidence: 0.890525533

00:35:02.120 --> 00:35:04.025 sentiment that most of the parents  
NOTE Confidence: 0.890525533

00:35:04.025 --> 00:35:05.735 in our study were really focused.

NOTE Confidence: 0.890525533

00:35:05.740 --> 00:35:07.225 On getting through this right

NOTE Confidence: 0.890525533

00:35:07.225 --> 00:35:09.433 now and there wasn't a lot of

NOTE Confidence: 0.890525533

00:35:09.433 --> 00:35:11.088 concern or consideration for what

NOTE Confidence: 0.890525533

00:35:11.088 --> 00:35:12.659 might happen down the road,

NOTE Confidence: 0.890525533

00:35:12.660 --> 00:35:14.505 or for what the child might think about this.

NOTE Confidence: 0.890525533

00:35:14.510 --> 00:35:14.766 Someday,

NOTE Confidence: 0.890525533

00:35:14.766 --> 00:35:16.814 one parent did think that this was going

NOTE Confidence: 0.890525533

00:35:16.814 --> 00:35:18.715 to be a really great record for her

NOTE Confidence: 0.890525533

00:35:18.715 --> 00:35:20.577 child to look back on her experience,

NOTE Confidence: 0.890525533

00:35:20.580 --> 00:35:22.596 but most people were not worried about,

NOTE Confidence: 0.890525533

00:35:22.600 --> 00:35:24.640 say, their child's first romantic partner.

NOTE Confidence: 0.890525533

00:35:24.640 --> 00:35:27.748 Googling this and finding really extensive

NOTE Confidence: 0.890525533

00:35:27.748 --> 00:35:31.170 information or anything like that.

NOTE Confidence: 0.890525533

00:35:31.170 --> 00:35:31.816 And finally,

NOTE Confidence: 0.890525533

00:35:31.816 --> 00:35:33.754 this one is from our hospital

NOTE Confidence: 0.890525533

00:35:33.754 --> 00:35:35.951 several years ago and it is one of  
NOTE Confidence: 0.890525533

00:35:35.951 --> 00:35:37.651 these sort of inciting events that  
NOTE Confidence: 0.890525533

00:35:37.651 --> 00:35:39.589 really got me interested in social  
NOTE Confidence: 0.890525533

00:35:39.589 --> 00:35:41.293 media and social media ethics,  
NOTE Confidence: 0.890525533

00:35:41.293 --> 00:35:44.175 so this was a teenager who had had  
NOTE Confidence: 0.890525533

00:35:44.175 --> 00:35:45.930 had a really prolonged hospital  
NOTE Confidence: 0.890525533

00:35:45.930 --> 00:35:48.509 stay with a lot of complications  
NOTE Confidence: 0.890525533

00:35:48.510 --> 00:35:50.688 and his parents took to Twitter  
NOTE Confidence: 0.890525533

00:35:50.688 --> 00:35:52.570 to vent about their care.  
NOTE Confidence: 0.890525533

00:35:52.570 --> 00:35:55.900 All the while actively refusing certain  
NOTE Confidence: 0.890525533

00:35:55.900 --> 00:35:58.120 interventions and requesting others.  
NOTE Confidence: 0.890525533

00:35:58.120 --> 00:36:01.130 And this is a timeline from diagnosis.  
NOTE Confidence: 0.890525533

00:36:01.130 --> 00:36:04.077 To win the patient was finally transferred.  
NOTE Confidence: 0.890525533

00:36:04.080 --> 00:36:07.027 It would lasted about 12 months altogether.  
NOTE Confidence: 0.890525533

00:36:07.030 --> 00:36:07.436 Uhm,  
NOTE Confidence: 0.890525533

00:36:07.436 --> 00:36:10.684 and around the time of the ICU admission.

NOTE Confidence: 0.890525533

00:36:10.690 --> 00:36:13.558 This is something the dad tweeted

NOTE Confidence: 0.890525533

00:36:13.560 --> 00:36:16.690 about the respiratory therapist and.

NOTE Confidence: 0.890525533

00:36:16.690 --> 00:36:18.166 Pretty soon after that,

NOTE Confidence: 0.890525533

00:36:18.166 --> 00:36:20.011 the staff discovered the Twitter

NOTE Confidence: 0.890525533

00:36:20.011 --> 00:36:20.989 feed and went.

NOTE Confidence: 0.890525533

00:36:20.990 --> 00:36:24.104 When he tweeted, can any idiot be a nurse?

NOTE Confidence: 0.890525533

00:36:24.110 --> 00:36:26.515 He started tweeting about making

NOTE Confidence: 0.890525533

00:36:26.515 --> 00:36:29.340 staff cry and reveling in that

NOTE Confidence: 0.890525533

00:36:29.340 --> 00:36:30.936 sometimes verged on threats,

NOTE Confidence: 0.890525533

00:36:30.936 --> 00:36:33.910 but the general consensus was they weren't.

NOTE Confidence: 0.890525533

00:36:33.910 --> 00:36:36.374 It was a dad venting and not someone

NOTE Confidence: 0.890525533

00:36:36.374 --> 00:36:38.030 who was actually specifically

NOTE Confidence: 0.890525533

00:36:38.030 --> 00:36:40.445 threatening anyone but at the

NOTE Confidence: 0.890525533

00:36:40.445 --> 00:36:42.809 same time through all of this,

NOTE Confidence: 0.890525533

00:36:42.810 --> 00:36:44.840 the staff were checking people were going

NOTE Confidence: 0.890525533

00:36:44.840 --> 00:36:46.939 on line between shifts or even between.  
NOTE Confidence: 0.890525533

00:36:46.940 --> 00:36:50.212 Patient seeing what did he tweet now and  
NOTE Confidence: 0.890525533

00:36:50.212 --> 00:36:53.338 it really contributed to an atmosphere  
NOTE Confidence: 0.890525533

00:36:53.338 --> 00:36:56.674 of tremendous stress of moral distress.  
NOTE Confidence: 0.890525533

00:36:56.680 --> 00:36:58.400 I we at that point had several nurses  
NOTE Confidence: 0.890525533

00:36:58.400 --> 00:36:59.959 who were thinking about leaving,  
NOTE Confidence: 0.890525533

00:36:59.960 --> 00:37:01.574 either going to different units or  
NOTE Confidence: 0.890525533

00:37:01.574 --> 00:37:03.579 going to a different hospital entirely.  
NOTE Confidence: 0.890525533

00:37:03.580 --> 00:37:05.330 Other people describe to me throwing up  
NOTE Confidence: 0.890525533

00:37:05.330 --> 00:37:07.240 before they came in for a shift every day,  
NOTE Confidence: 0.890525533

00:37:07.240 --> 00:37:09.180 because this was so stressful,  
NOTE Confidence: 0.890525533

00:37:09.180 --> 00:37:11.124 and this is not we've always  
NOTE Confidence: 0.890525533

00:37:11.124 --> 00:37:12.440 had angry families, right?  
NOTE Confidence: 0.890525533

00:37:12.440 --> 00:37:14.480 This is not that that part  
NOTE Confidence: 0.890525533

00:37:14.480 --> 00:37:16.540 by itself is not uncommon.  
NOTE Confidence: 0.890525533

00:37:16.540 --> 00:37:17.578 The part where.

NOTE Confidence: 0.890525533

00:37:17.578 --> 00:37:19.308 Things that someone might have

NOTE Confidence: 0.890525533

00:37:19.308 --> 00:37:21.827 vented in a private phone call to

NOTE Confidence: 0.890525533

00:37:21.827 --> 00:37:23.587 another family member about their

NOTE Confidence: 0.890525533

00:37:23.656 --> 00:37:25.448 care about their frustration.

NOTE Confidence: 0.890525533

00:37:25.450 --> 00:37:26.995 We're now public and people

NOTE Confidence: 0.890525533

00:37:26.995 --> 00:37:28.540 feeling like anyone I know

NOTE Confidence: 0.92742357

00:37:28.605 --> 00:37:30.357 can see this can see the

NOTE Confidence: 0.92742357

00:37:30.357 --> 00:37:31.525 criticism of our hospital,

NOTE Confidence: 0.92742357

00:37:31.530 --> 00:37:33.210 our institution. That is very,

NOTE Confidence: 0.92742357

00:37:33.210 --> 00:37:35.926 very specific to social media and the

NOTE Confidence: 0.92742357

00:37:35.926 --> 00:37:39.186 way in which this played out in public.

NOTE Confidence: 0.92742357

00:37:39.190 --> 00:37:41.640 And finally, social media is an accelerator.

NOTE Confidence: 0.92742357

00:37:41.640 --> 00:37:44.027 So many of these will be familiar

NOTE Confidence: 0.92742357

00:37:44.027 --> 00:37:45.759 to people from the news.

NOTE Confidence: 0.92742357

00:37:45.760 --> 00:37:48.060 UM, so this one is a 7 year old who

NOTE Confidence: 0.92742357

00:37:48.134 --> 00:37:50.468 had a life threatening viral infection  
NOTE Confidence: 0.92742357

00:37:50.468 --> 00:37:53.079 was ineligible for a clinical trial,  
NOTE Confidence: 0.92742357

00:37:53.080 --> 00:37:55.018 and his parents successfully mounted a  
NOTE Confidence: 0.92742357

00:37:55.018 --> 00:37:57.079 social media campaign that pressured the  
NOTE Confidence: 0.92742357

00:37:57.079 --> 00:37:59.209 pharmaceutical company to provide the drug.  
NOTE Confidence: 0.92742357

00:37:59.210 --> 00:38:01.058 There are many more instances like that,  
NOTE Confidence: 0.92742357

00:38:01.060 --> 00:38:02.180 some successful,  
NOTE Confidence: 0.92742357

00:38:02.180 --> 00:38:03.860 not some unsuccessful,  
NOTE Confidence: 0.92742357

00:38:03.860 --> 00:38:05.848 but where parents after,  
NOTE Confidence: 0.92742357

00:38:05.848 --> 00:38:08.333 after disagreeing with their physician,  
NOTE Confidence: 0.92742357

00:38:08.340 --> 00:38:10.488 either with the intent of starting.  
NOTE Confidence: 0.92742357

00:38:10.490 --> 00:38:11.249 Such a campaign,  
NOTE Confidence: 0.92742357

00:38:11.249 --> 00:38:13.020 or just because they too are going  
NOTE Confidence: 0.92742357

00:38:13.071 --> 00:38:14.439 online to vent and it happens  
NOTE Confidence: 0.92742357

00:38:14.439 --> 00:38:16.050 to get picked up and go viral.  
NOTE Confidence: 0.92742357

00:38:16.050 --> 00:38:18.170 The conflict really accelerates and

NOTE Confidence: 0.92742357

00:38:18.170 --> 00:38:20.731 really starts to push people into

NOTE Confidence: 0.92742357

00:38:20.731 --> 00:38:23.328 corners and away from the kinds of

NOTE Confidence: 0.92742357

00:38:23.328 --> 00:38:25.652 compromises that we normally think of

NOTE Confidence: 0.92742357

00:38:25.652 --> 00:38:27.920 as a good solution to disagreements.

NOTE Confidence: 0.92742357

00:38:27.920 --> 00:38:29.498 One parent that this is just

NOTE Confidence: 0.92742357

00:38:29.498 --> 00:38:30.960 one parent in our study.

NOTE Confidence: 0.92742357

00:38:30.960 --> 00:38:33.746 I and I do not think representative

NOTE Confidence: 0.92742357

00:38:33.746 --> 00:38:34.940 overall of parents,

NOTE Confidence: 0.92742357

00:38:34.940 --> 00:38:37.550 but I think this quote shares a lot in

NOTE Confidence: 0.92742357

00:38:37.550 --> 00:38:40.160 common with those conflicts that go viral.

NOTE Confidence: 0.92742357

00:38:40.160 --> 00:38:41.141 And she wrote.

NOTE Confidence: 0.92742357

00:38:41.141 --> 00:38:42.776 I've pushed very hard for

NOTE Confidence: 0.92742357

00:38:42.776 --> 00:38:43.430 alternative options.

NOTE Confidence: 0.92742357

00:38:43.430 --> 00:38:45.506 Many that go against hospital policy,

NOTE Confidence: 0.92742357

00:38:45.510 --> 00:38:46.558 too many to list,

NOTE Confidence: 0.92742357

00:38:46.558 --> 00:38:48.498 but I've informed them that we are  
NOTE Confidence: 0.92742357

00:38:48.498 --> 00:38:50.370 pushing things directly into the G2.  
NOTE Confidence: 0.92742357

00:38:50.370 --> 00:38:52.393 I'm careful not to ask permission or  
NOTE Confidence: 0.92742357

00:38:52.393 --> 00:38:54.529 opinions because I know what they will be.  
NOTE Confidence: 0.92742357

00:38:54.530 --> 00:38:55.589 I'm very assertive.  
NOTE Confidence: 0.92742357

00:38:55.589 --> 00:38:57.707 They also know my blog exists.  
NOTE Confidence: 0.92742357

00:38:57.710 --> 00:38:59.290 With 100,000 plus followers  
NOTE Confidence: 0.92742357

00:38:59.290 --> 00:39:00.475 with daily updates,  
NOTE Confidence: 0.92742357

00:39:00.480 --> 00:39:02.538 so I think that's in my corner,  
NOTE Confidence: 0.92742357

00:39:02.540 --> 00:39:05.044 so the sense was that she felt that  
NOTE Confidence: 0.92742357

00:39:05.044 --> 00:39:07.173 having this large following helped her  
NOTE Confidence: 0.92742357

00:39:07.173 --> 00:39:09.999 get what she want from from the team,  
NOTE Confidence: 0.92742357

00:39:10.000 --> 00:39:11.650 and it actually helped help prevent  
NOTE Confidence: 0.92742357

00:39:11.650 --> 00:39:13.390 the team from openly disagreeing,  
NOTE Confidence: 0.92742357

00:39:13.390 --> 00:39:16.176 though she knew that they might quietly  
NOTE Confidence: 0.92742357

00:39:16.176 --> 00:39:18.609 disagree with some of the decisions.

NOTE Confidence: 0.92742357

00:39:18.610 --> 00:39:21.002 So this list is from a paper that

NOTE Confidence: 0.92742357

00:39:21.002 --> 00:39:22.840 Brian Warren John Lantos published

NOTE Confidence: 0.92742357

00:39:22.840 --> 00:39:25.180 in Pediatrics a couple years ago

NOTE Confidence: 0.92742357

00:39:25.180 --> 00:39:27.386 where they looked at 12 different

NOTE Confidence: 0.92742357

00:39:27.386 --> 00:39:29.442 cases that went that went viral.

NOTE Confidence: 0.92742357

00:39:29.442 --> 00:39:31.446 So cases of conflict that became

NOTE Confidence: 0.92742357

00:39:31.446 --> 00:39:33.730 very public and they looked at

NOTE Confidence: 0.92742357

00:39:33.730 --> 00:39:35.615 reasons parents said they initiated

NOTE Confidence: 0.92742357

00:39:35.684 --> 00:39:37.480 their social media campaigns,

NOTE Confidence: 0.92742357

00:39:37.480 --> 00:39:39.286 the first and maybe the most obvious

NOTE Confidence: 0.92742357

00:39:39.286 --> 00:39:41.278 is just to change doctors minds.

NOTE Confidence: 0.92742357

00:39:41.280 --> 00:39:42.628 But some of these,

NOTE Confidence: 0.92742357

00:39:42.628 --> 00:39:45.083 particularly the idea of being heard of

NOTE Confidence: 0.92742357

00:39:45.083 --> 00:39:47.659 feeling empowered and feeling that they have.

NOTE Confidence: 0.92742357

00:39:47.660 --> 00:39:48.902 Done everything possible,

NOTE Confidence: 0.92742357

00:39:48.902 --> 00:39:51.386 really overlap with things all over  
NOTE Confidence: 0.92742357

00:39:51.386 --> 00:39:53.697 the parents in our study said about  
NOTE Confidence: 0.92742357

00:39:53.697 --> 00:39:56.494 why they turn to social media and how  
NOTE Confidence: 0.92742357

00:39:56.494 --> 00:39:58.750 they think social media benefits them.  
NOTE Confidence: 0.92742357

00:39:58.750 --> 00:40:01.230 Another parent wrote we as a family have  
NOTE Confidence: 0.92742357

00:40:01.230 --> 00:40:03.149 had situations in a smaller hospital,  
NOTE Confidence: 0.92742357

00:40:03.150 --> 00:40:05.185 and so it was nice to be able to go to my  
NOTE Confidence: 0.92742357

00:40:05.185 --> 00:40:06.897 Facebook group and be like is this normal?  
NOTE Confidence: 0.92742357

00:40:06.900 --> 00:40:07.905 Is this OK?  
NOTE Confidence: 0.92742357

00:40:07.905 --> 00:40:08.910 Is this right?  
NOTE Confidence: 0.92742357

00:40:08.910 --> 00:40:10.350 And then get a parents opinion?  
NOTE Confidence: 0.92742357

00:40:10.350 --> 00:40:11.638 Who says absolutely not?  
NOTE Confidence: 0.92742357

00:40:11.638 --> 00:40:12.604 Don't leave there,  
NOTE Confidence: 0.92742357

00:40:12.610 --> 00:40:13.090 you know,  
NOTE Confidence: 0.92742357

00:40:13.090 --> 00:40:13.810 stand your ground.  
NOTE Confidence: 0.92742357

00:40:13.810 --> 00:40:15.330 I'm sorry you're going through

NOTE Confidence: 0.92742357

00:40:15.330 --> 00:40:16.850 this and so this parent

NOTE Confidence: 0.918784045625

00:40:16.907 --> 00:40:19.439 was really describing that empowerment piece.

NOTE Confidence: 0.918784045625

00:40:19.440 --> 00:40:21.708 That feeling of when they were not

NOTE Confidence: 0.918784045625

00:40:21.708 --> 00:40:24.143 sure whether they should be entrenched

NOTE Confidence: 0.918784045625

00:40:24.143 --> 00:40:26.562 themselves in the disagreement, or whether

NOTE Confidence: 0.918784045625

00:40:26.562 --> 00:40:28.529 hey maybe the team is actually right.

NOTE Confidence: 0.918784045625

00:40:28.530 --> 00:40:30.266 And we should agree to what they want.

NOTE Confidence: 0.918784045625

00:40:30.270 --> 00:40:33.094 They went online and they got support to

NOTE Confidence: 0.918784045625

00:40:33.094 --> 00:40:35.740 bolster that resistance or that conflict.

NOTE Confidence: 0.918784045625

00:40:35.740 --> 00:40:37.522 And that is very much social

NOTE Confidence: 0.918784045625

00:40:37.522 --> 00:40:39.540 media acting as an accelerator.

NOTE Confidence: 0.918784045625

00:40:39.540 --> 00:40:42.828 Uh, so how should we respond?

NOTE Confidence: 0.918784045625

00:40:42.830 --> 00:40:44.510 First we need we need to accept

NOTE Confidence: 0.918784045625

00:40:44.510 --> 00:40:46.347 the things we cannot change and I,

NOTE Confidence: 0.918784045625

00:40:46.350 --> 00:40:47.970 I mean that really seriously,

NOTE Confidence: 0.918784045625

00:40:47.970 --> 00:40:49.727 social media is here to stay and  
NOTE Confidence: 0.918784045625

00:40:49.727 --> 00:40:52.126 I I have a 9 year old so I very  
NOTE Confidence: 0.918784045625

00:40:52.126 --> 00:40:53.935 much hope that some things work  
NOTE Confidence: 0.918784045625

00:40:53.935 --> 00:40:56.059 themselves out before he is online.  
NOTE Confidence: 0.918784045625

00:40:56.060 --> 00:40:57.806 A lot in a few years,  
NOTE Confidence: 0.918784045625

00:40:57.810 --> 00:41:00.246 but I also know that's probably pretty  
NOTE Confidence: 0.918784045625

00:41:00.246 --> 00:41:02.157 unrealistic and we're going to be  
NOTE Confidence: 0.918784045625

00:41:02.157 --> 00:41:04.026 stuck with this for the long haul.  
NOTE Confidence: 0.918784045625

00:41:04.030 --> 00:41:05.990 And really, we should remove the phrase.  
NOTE Confidence: 0.918784045625

00:41:05.990 --> 00:41:08.139 Just don't go on online from our  
NOTE Confidence: 0.918784045625

00:41:08.139 --> 00:41:09.988 repertoire that that is not a  
NOTE Confidence: 0.918784045625

00:41:09.988 --> 00:41:11.433 helpful statement for the vast,  
NOTE Confidence: 0.918784045625

00:41:11.440 --> 00:41:13.208 vast majority of families.  
NOTE Confidence: 0.918784045625

00:41:13.208 --> 00:41:15.860 And it's actually pretty dismissive and  
NOTE Confidence: 0.918784045625

00:41:15.935 --> 00:41:18.065 closes off the kinds of conversations  
NOTE Confidence: 0.918784045625

00:41:18.065 --> 00:41:20.913 we want to have with families in

NOTE Confidence: 0.918784045625

00:41:20.913 --> 00:41:23.173 order to prevent these disagreements.

NOTE Confidence: 0.918784045625

00:41:23.180 --> 00:41:24.770 We need to do more anticipatory

NOTE Confidence: 0.918784045625

00:41:24.770 --> 00:41:26.531 guidance and I'm going to show you

NOTE Confidence: 0.918784045625

00:41:26.531 --> 00:41:28.043 in a moment how families tell me

NOTE Confidence: 0.918784045625

00:41:28.094 --> 00:41:29.624 they assess credibility so we can

NOTE Confidence: 0.918784045625

00:41:29.624 --> 00:41:31.715 compare it to what we think would

NOTE Confidence: 0.918784045625

00:41:31.715 --> 00:41:33.135 be actually meaningful assessment

NOTE Confidence: 0.918784045625

00:41:33.135 --> 00:41:34.910 of credibility of information.

NOTE Confidence: 0.918784045625

00:41:34.910 --> 00:41:36.290 But they need those skills.

NOTE Confidence: 0.918784045625

00:41:36.290 --> 00:41:38.327 How do we assess credibility of information?

NOTE Confidence: 0.918784045625

00:41:38.330 --> 00:41:41.000 How do we identify misinformation?

NOTE Confidence: 0.918784045625

00:41:41.000 --> 00:41:43.046 Parents need to know more about

NOTE Confidence: 0.918784045625

00:41:43.046 --> 00:41:44.069 the privacy risks.

NOTE Confidence: 0.918784045625

00:41:44.070 --> 00:41:46.604 Many parents in our study describes some

NOTE Confidence: 0.918784045625

00:41:46.604 --> 00:41:48.769 degree of harassment happening online.

NOTE Confidence: 0.918784045625

00:41:48.770 --> 00:41:50.730 Some talked about identity theft,  
NOTE Confidence: 0.918784045625

00:41:50.730 --> 00:41:52.178 but those are things that a lot of  
NOTE Confidence: 0.918784045625

00:41:52.178 --> 00:41:53.733 other parents said. Hey, I never.  
NOTE Confidence: 0.918784045625

00:41:53.733 --> 00:41:55.659 Thought about that when I was  
NOTE Confidence: 0.918784045625

00:41:55.659 --> 00:41:57.547 thinking about crowdfunding or making  
NOTE Confidence: 0.918784045625

00:41:57.547 --> 00:41:59.803 a public blog about our journey,  
NOTE Confidence: 0.918784045625

00:41:59.810 --> 00:42:01.954 and many of them had not really thought  
NOTE Confidence: 0.918784045625

00:42:01.954 --> 00:42:03.856 about the right to an open future.  
NOTE Confidence: 0.918784045625

00:42:03.860 --> 00:42:05.635 The right to future privacy  
NOTE Confidence: 0.918784045625

00:42:05.635 --> 00:42:06.700 for their children.  
NOTE Confidence: 0.918784045625

00:42:06.700 --> 00:42:08.446 So those are all things we  
NOTE Confidence: 0.918784045625

00:42:08.446 --> 00:42:10.107 could be doing more education  
NOTE Confidence: 0.918784045625

00:42:10.107 --> 00:42:12.267 about in hospitals and clinics.  
NOTE Confidence: 0.918784045625

00:42:12.270 --> 00:42:14.880 So one more it's might be my last quote,  
NOTE Confidence: 0.918784045625

00:42:14.880 --> 00:42:15.840 but this mom wrote.  
NOTE Confidence: 0.918784045625

00:42:15.840 --> 00:42:17.775 I deleted my post because there was this

NOTE Confidence: 0.918784045625

00:42:17.775 --> 00:42:19.543 influx of like that's not a good test.

NOTE Confidence: 0.918784045625

00:42:19.550 --> 00:42:20.540 And why would you do that?

NOTE Confidence: 0.918784045625

00:42:20.540 --> 00:42:21.850 And that's awful and you

NOTE Confidence: 0.918784045625

00:42:21.850 --> 00:42:22.636 need something better.

NOTE Confidence: 0.918784045625

00:42:22.640 --> 00:42:24.369 And then that sends you into panic

NOTE Confidence: 0.918784045625

00:42:24.369 --> 00:42:25.570 mode because you're like who?

NOTE Confidence: 0.918784045625

00:42:25.570 --> 00:42:27.622 Maybe we didn't make the right

NOTE Confidence: 0.918784045625

00:42:27.622 --> 00:42:29.146 choice and when she was saying this,

NOTE Confidence: 0.918784045625

00:42:29.150 --> 00:42:30.545 I thought this is something

NOTE Confidence: 0.918784045625

00:42:30.545 --> 00:42:32.713 that we might have been able to

NOTE Confidence: 0.918784045625

00:42:32.713 --> 00:42:34.137 anticipate with more education.

NOTE Confidence: 0.918784045625

00:42:34.140 --> 00:42:35.932 We might have been able to help

NOTE Confidence: 0.918784045625

00:42:35.932 --> 00:42:37.710 this parent be prepared for this

NOTE Confidence: 0.918784045625

00:42:37.710 --> 00:42:39.565 and maybe be a little bit more

NOTE Confidence: 0.918784045625

00:42:39.565 --> 00:42:41.327 judicious and what she asked online

NOTE Confidence: 0.918784045625

00:42:41.327 --> 00:42:42.847 or what kind of information?  
NOTE Confidence: 0.918784045625

00:42:42.850 --> 00:42:44.789 Did she thought or just make her  
NOTE Confidence: 0.918784045625

00:42:44.789 --> 00:42:47.087 prepared for the fact that she might  
NOTE Confidence: 0.918784045625

00:42:47.087 --> 00:42:48.491 find conflicting information and  
NOTE Confidence: 0.918784045625

00:42:48.491 --> 00:42:50.421 she might hear from other parents  
NOTE Confidence: 0.918784045625

00:42:50.421 --> 00:42:51.902 who say something's not right when  
NOTE Confidence: 0.918784045625

00:42:51.902 --> 00:42:53.240 something really is the best thing  
NOTE Confidence: 0.935919125384615

00:42:53.286 --> 00:42:53.799 for her child?  
NOTE Confidence: 0.947382391818182

00:42:55.850 --> 00:42:58.202 So this is how parents tell us  
NOTE Confidence: 0.947382391818182

00:42:58.202 --> 00:43:00.140 they check their information.  
NOTE Confidence: 0.947382391818182

00:43:00.140 --> 00:43:02.000 So many parents reported  
NOTE Confidence: 0.947382391818182

00:43:02.000 --> 00:43:02.930 verifying information,  
NOTE Confidence: 0.947382391818182

00:43:02.930 --> 00:43:05.195 though not always with a  
NOTE Confidence: 0.947382391818182

00:43:05.195 --> 00:43:07.007 physician or professional source.  
NOTE Confidence: 0.947382391818182

00:43:07.010 --> 00:43:07.916 But many did.  
NOTE Confidence: 0.947382391818182

00:43:07.916 --> 00:43:09.728 Very often they verified it with

NOTE Confidence: 0.947382391818182  
00:43:09.728 --> 00:43:11.682 either other parents of children with  
NOTE Confidence: 0.947382391818182  
00:43:11.682 --> 00:43:14.360 cancer or just with their family or friends.  
NOTE Confidence: 0.947382391818182  
00:43:14.360 --> 00:43:16.397 Many said they thought about the level  
NOTE Confidence: 0.947382391818182  
00:43:16.397 --> 00:43:18.441 of urgency and potential impact and  
NOTE Confidence: 0.947382391818182  
00:43:18.441 --> 00:43:20.286 that their approach was different  
NOTE Confidence: 0.947382391818182  
00:43:20.286 --> 00:43:22.240 depending on how urgently they  
NOTE Confidence: 0.947382391818182  
00:43:22.240 --> 00:43:25.240 needed to act on the information.  
NOTE Confidence: 0.947382391818182  
00:43:25.240 --> 00:43:26.950 And they all described checking for  
NOTE Confidence: 0.947382391818182  
00:43:26.950 --> 00:43:28.673 what they thought were characteristics  
NOTE Confidence: 0.947382391818182  
00:43:28.673 --> 00:43:30.260 of trustworthy information.  
NOTE Confidence: 0.947382391818182  
00:43:30.260 --> 00:43:30.730 Unfortunately,  
NOTE Confidence: 0.947382391818182  
00:43:30.730 --> 00:43:33.080 many of those characteristics are  
NOTE Confidence: 0.947382391818182  
00:43:33.080 --> 00:43:34.960 also reasons that information  
NOTE Confidence: 0.947382391818182  
00:43:35.022 --> 00:43:36.648 and misinformation spreads.  
NOTE Confidence: 0.947382391818182  
00:43:36.650 --> 00:43:40.010 A man and and can go viral online,  
NOTE Confidence: 0.947382391818182

00:43:40.010 --> 00:43:41.760 so most parents liked first-hand  
NOTE Confidence: 0.947382391818182

00:43:41.760 --> 00:43:43.510 information so they didn't want  
NOTE Confidence: 0.947382391818182

00:43:43.574 --> 00:43:44.778 to hear about someone.  
NOTE Confidence: 0.947382391818182

00:43:44.780 --> 00:43:46.740 Step mothers, cousins best friend.  
NOTE Confidence: 0.947382391818182

00:43:46.740 --> 00:43:48.132 They wanted to hear from people  
NOTE Confidence: 0.947382391818182

00:43:48.132 --> 00:43:49.240 saying this worked for me,  
NOTE Confidence: 0.947382391818182

00:43:49.240 --> 00:43:51.040 or this worked for my child.  
NOTE Confidence: 0.947382391818182

00:43:51.040 --> 00:43:52.860 They found more detailed information  
NOTE Confidence: 0.947382391818182

00:43:52.860 --> 00:43:55.290 to be more accurate and which is.  
NOTE Confidence: 0.947382391818182

00:43:55.290 --> 00:43:57.390 Not necessarily backed up by anything,  
NOTE Confidence: 0.947382391818182

00:43:57.390 --> 00:43:59.470 but I can see why that would be.  
NOTE Confidence: 0.947382391818182

00:43:59.470 --> 00:44:00.980 They looked for current and  
NOTE Confidence: 0.947382391818182

00:44:00.980 --> 00:44:01.584 up-to-date information,  
NOTE Confidence: 0.947382391818182

00:44:01.590 --> 00:44:03.462 so that was good and they  
NOTE Confidence: 0.947382391818182

00:44:03.462 --> 00:44:04.710 looked for converging opinions,  
NOTE Confidence: 0.947382391818182

00:44:04.710 --> 00:44:07.540 which for some families meant.

NOTE Confidence: 0.947382391818182  
00:44:07.540 --> 00:44:09.245 Apparent recommending the same thing  
NOTE Confidence: 0.947382391818182  
00:44:09.245 --> 00:44:11.700 that they also saw show up on WebMD,  
NOTE Confidence: 0.947382391818182  
00:44:11.700 --> 00:44:14.340 but for other people just meant the same  
NOTE Confidence: 0.947382391818182  
00:44:14.340 --> 00:44:16.540 information being posted in multiple places,  
NOTE Confidence: 0.947382391818182  
00:44:16.540 --> 00:44:18.172 which is often just a sign  
NOTE Confidence: 0.947382391818182  
00:44:18.172 --> 00:44:19.650 that something has gone viral.  
NOTE Confidence: 0.947382391818182  
00:44:19.650 --> 00:44:21.226 That something has those  
NOTE Confidence: 0.947382391818182  
00:44:21.226 --> 00:44:23.196 characteristics that make it spread.  
NOTE Confidence: 0.947382391818182  
00:44:23.200 --> 00:44:25.990 So I think we can do better in training  
NOTE Confidence: 0.947382391818182  
00:44:25.990 --> 00:44:28.499 families to identify credible information,  
NOTE Confidence: 0.947382391818182  
00:44:28.500 --> 00:44:30.438 but our family is also talked  
NOTE Confidence: 0.947382391818182  
00:44:30.438 --> 00:44:32.536 about what they considered to be  
NOTE Confidence: 0.947382391818182  
00:44:32.536 --> 00:44:34.386 positive and negative responses from  
NOTE Confidence: 0.947382391818182  
00:44:34.386 --> 00:44:36.281 their physicians when they brought  
NOTE Confidence: 0.947382391818182  
00:44:36.281 --> 00:44:38.096 up these areas of disagreement.  
NOTE Confidence: 0.947382391818182

00:44:38.100 --> 00:44:40.680 Are conflicting information or said hey,  
NOTE Confidence: 0.947382391818182

00:44:40.680 --> 00:44:43.138 I want to try this so positive  
NOTE Confidence: 0.947382391818182

00:44:43.138 --> 00:44:44.958 responses were pretty much anytime  
NOTE Confidence: 0.947382391818182

00:44:44.958 --> 00:44:47.086 anyone was willing to answer questions  
NOTE Confidence: 0.947382391818182

00:44:47.086 --> 00:44:49.036 and didn't avoid the discussion or  
NOTE Confidence: 0.947382391818182

00:44:49.036 --> 00:44:51.129 not answer the question when they  
NOTE Confidence: 0.947382391818182

00:44:51.129 --> 00:44:53.176 listened and showed an interest in  
NOTE Confidence: 0.947382391818182

00:44:53.176 --> 00:44:54.856 what the parent learned online.  
NOTE Confidence: 0.947382391818182

00:44:54.860 --> 00:44:56.440 When they affirmed the importance  
NOTE Confidence: 0.947382391818182

00:44:56.440 --> 00:44:58.020 of parental education so parents  
NOTE Confidence: 0.947382391818182

00:44:58.069 --> 00:44:59.389 felt better when people said hey  
NOTE Confidence: 0.947382391818182

00:44:59.389 --> 00:45:01.237 you you did a good thing for your  
NOTE Confidence: 0.947382391818182

00:45:01.237 --> 00:45:02.993 child by trying to go online trying  
NOTE Confidence: 0.947382391818182

00:45:02.993 --> 00:45:05.496 to do your own research and they  
NOTE Confidence: 0.947382391818182

00:45:05.496 --> 00:45:07.086 valued when people either offered  
NOTE Confidence: 0.947382391818182

00:45:07.086 --> 00:45:08.809 to modify treatment so saying hey.

NOTE Confidence: 0.947382391818182  
00:45:08.810 --> 00:45:10.106 Well, that won't hurt,  
NOTE Confidence: 0.947382391818182  
00:45:10.106 --> 00:45:12.853 so let's try it or referring for a  
NOTE Confidence: 0.947382391818182  
00:45:12.853 --> 00:45:15.049 second opinion to check the information.  
NOTE Confidence: 0.947382391818182  
00:45:15.050 --> 00:45:16.050 And on the flip side,  
NOTE Confidence: 0.947382391818182  
00:45:16.050 --> 00:45:17.550 they didn't like the opposites.  
NOTE Confidence: 0.947382391818182  
00:45:17.550 --> 00:45:18.955 They didn't like when people  
NOTE Confidence: 0.947382391818182  
00:45:18.955 --> 00:45:20.680 became angry or yelled at them,  
NOTE Confidence: 0.947382391818182  
00:45:20.680 --> 00:45:22.190 which happened several times or  
NOTE Confidence: 0.947382391818182  
00:45:22.190 --> 00:45:24.230 when they were just told to not  
NOTE Confidence: 0.947382391818182  
00:45:24.230 --> 00:45:25.868 go online to not worry about it,  
NOTE Confidence: 0.947382391818182  
00:45:25.870 --> 00:45:26.821 to dismiss it.  
NOTE Confidence: 0.947382391818182  
00:45:26.821 --> 00:45:28.723 Most parents could not dismiss it,  
NOTE Confidence: 0.947382391818182  
00:45:28.730 --> 00:45:31.270 they hung onto it.  
NOTE Confidence: 0.947382391818182  
00:45:31.270 --> 00:45:33.808 And they also described ways in  
NOTE Confidence: 0.947382391818182  
00:45:33.808 --> 00:45:35.500 which certain responses promoted  
NOTE Confidence: 0.947382391818182

00:45:35.567 --> 00:45:38.297 their trust and ways in which other  
NOTE Confidence: 0.947382391818182

00:45:38.297 --> 00:45:40.326 responses negated trust and the  
NOTE Confidence: 0.947382391818182

00:45:40.326 --> 00:45:42.306 big ones were overall openness  
NOTE Confidence: 0.947382391818182

00:45:42.306 --> 00:45:43.494 to these discussions.  
NOTE Confidence: 0.947382391818182

00:45:43.500 --> 00:45:46.820 Honesty, transparency, and humility.  
NOTE Confidence: 0.947382391818182

00:45:46.820 --> 00:45:49.520 So one parent described oncologists saying,  
NOTE Confidence: 0.947382391818182

00:45:49.520 --> 00:45:50.328 I can't answer that.  
NOTE Confidence: 0.947382391818182

00:45:50.328 --> 00:45:51.136 That's a great question.  
NOTE Confidence: 0.953524516

00:45:51.140 --> 00:45:53.760 I don't have the answer and that they  
NOTE Confidence: 0.953524516

00:45:53.760 --> 00:45:55.560 were consistently willing to do that.  
NOTE Confidence: 0.953524516

00:45:55.560 --> 00:45:57.080 Really helped the family trust  
NOTE Confidence: 0.953524516

00:45:57.080 --> 00:45:58.600 this physician and know that  
NOTE Confidence: 0.953524516

00:45:58.658 --> 00:46:00.308 when they didn't give a correct.  
NOTE Confidence: 0.953524516

00:46:00.310 --> 00:46:01.738 When they did give an answer,  
NOTE Confidence: 0.953524516

00:46:01.740 --> 00:46:03.480 they could feel confident that it  
NOTE Confidence: 0.953524516

00:46:03.480 --> 00:46:05.437 wasn't something just made up that it

NOTE Confidence: 0.953524516

00:46:05.437 --> 00:46:06.919 was a real meaningful answer because

NOTE Confidence: 0.953524516

00:46:06.919 --> 00:46:08.571 the physician was also willing to

NOTE Confidence: 0.953524516

00:46:08.571 --> 00:46:10.830 stay when they didn't know the answer

NOTE Confidence: 0.953524516

00:46:10.830 --> 00:46:13.080 and finally shared decision making.

NOTE Confidence: 0.931317329333333

00:46:15.460 --> 00:46:17.259 So from from all of that data

NOTE Confidence: 0.931317329333333

00:46:17.259 --> 00:46:19.327 and from the parents responses to

NOTE Confidence: 0.931317329333333

00:46:19.327 --> 00:46:21.787 questions about what they would tell

NOTE Confidence: 0.931317329333333

00:46:21.787 --> 00:46:23.952 providers and what they would tell

NOTE Confidence: 0.931317329333333

00:46:23.952 --> 00:46:25.975 other families we put together these

NOTE Confidence: 0.931317329333333

00:46:25.975 --> 00:46:27.650 eight recommendations and I'm going

NOTE Confidence: 0.931317329333333

00:46:27.650 --> 00:46:29.886 to highlight the ones that I think

NOTE Confidence: 0.931317329333333

00:46:29.886 --> 00:46:31.572 are most important to our discussions

NOTE Confidence: 0.931317329333333

00:46:31.572 --> 00:46:33.348 of conflict and disagreements.

NOTE Confidence: 0.931317329333333

00:46:33.350 --> 00:46:34.939 And the first is that idea of

NOTE Confidence: 0.931317329333333

00:46:34.939 --> 00:46:36.100 being open to parents,

NOTE Confidence: 0.931317329333333

00:46:36.100 --> 00:46:38.215 asking questions and raising concerns  
NOTE Confidence: 0.9313173293333333

00:46:38.215 --> 00:46:40.750 based upon information from social media.  
NOTE Confidence: 0.9313173293333333

00:46:40.750 --> 00:46:42.388 The second is being honest about  
NOTE Confidence: 0.9313173293333333

00:46:42.388 --> 00:46:44.149 what we know and don't know.  
NOTE Confidence: 0.9313173293333333

00:46:44.150 --> 00:46:45.110 And and for this one.  
NOTE Confidence: 0.9313173293333333

00:46:45.110 --> 00:46:46.795 The parents wrote we'll probably  
NOTE Confidence: 0.9313173293333333

00:46:46.795 --> 00:46:48.143 Google everything you say,  
NOTE Confidence: 0.9313173293333333

00:46:48.150 --> 00:46:49.878 or at least check it with our networks  
NOTE Confidence: 0.9313173293333333

00:46:49.878 --> 00:46:51.708 and other parents and it's not personal.  
NOTE Confidence: 0.9313173293333333

00:46:51.710 --> 00:46:53.858 It doesn't mean we trust you,  
NOTE Confidence: 0.9313173293333333

00:46:53.860 --> 00:46:55.444 and in fact it could be a sign that  
NOTE Confidence: 0.9313173293333333

00:46:55.444 --> 00:46:57.082 we do trust you because we're going  
NOTE Confidence: 0.9313173293333333

00:46:57.082 --> 00:46:58.810 to work it through when we hear  
NOTE Confidence: 0.9313173293333333

00:46:58.810 --> 00:47:00.280 things we don't understand or get  
NOTE Confidence: 0.9313173293333333

00:47:00.280 --> 00:47:02.500 advice that we're not sure about.  
NOTE Confidence: 0.9313173293333333

00:47:02.500 --> 00:47:04.660 They also suggested using social

NOTE Confidence: 0.931317329333333

00:47:04.660 --> 00:47:06.950 media ourselves, and I have done this.

NOTE Confidence: 0.931317329333333

00:47:06.950 --> 00:47:08.522 I suspect many people in this

NOTE Confidence: 0.931317329333333

00:47:08.522 --> 00:47:09.570 audience have done this,

NOTE Confidence: 0.931317329333333

00:47:09.570 --> 00:47:11.226 but it really does help give

NOTE Confidence: 0.931317329333333

00:47:11.226 --> 00:47:12.330 some insight into families,

NOTE Confidence: 0.931317329333333

00:47:12.330 --> 00:47:13.682 perspectives and into what

NOTE Confidence: 0.931317329333333

00:47:13.682 --> 00:47:15.372 the what kind of information.

NOTE Confidence: 0.931317329333333

00:47:15.380 --> 00:47:18.878 Was readily accessible to families online,

NOTE Confidence: 0.931317329333333

00:47:18.880 --> 00:47:21.193 but they warned us if we do be cautious

NOTE Confidence: 0.931317329333333

00:47:21.193 --> 00:47:23.880 and take care of ourselves and I really

NOTE Confidence: 0.931317329333333

00:47:23.880 --> 00:47:25.280 appreciated that consideration that

NOTE Confidence: 0.931317329333333

00:47:25.280 --> 00:47:27.508 many of the parents thought about

NOTE Confidence: 0.931317329333333

00:47:27.508 --> 00:47:29.746 how overwhelming social media was for

NOTE Confidence: 0.931317329333333

00:47:29.746 --> 00:47:32.558 them and consider that it might be

NOTE Confidence: 0.931317329333333

00:47:32.558 --> 00:47:34.142 equally overwhelming for pediatricians

NOTE Confidence: 0.931317329333333

00:47:34.150 --> 00:47:37.580 and other professionals going online.  
NOTE Confidence: 0.9313173293333333

00:47:37.580 --> 00:47:38.369 And they said,  
NOTE Confidence: 0.9313173293333333

00:47:38.369 --> 00:47:38.632 no,  
NOTE Confidence: 0.9313173293333333

00:47:38.632 --> 00:47:40.529 that it's OK if sometimes they prefer  
NOTE Confidence: 0.9313173293333333

00:47:40.529 --> 00:47:42.370 to look up what we said rather  
NOTE Confidence: 0.9313173293333333

00:47:42.370 --> 00:47:44.080 than asking about it immediately,  
NOTE Confidence: 0.9313173293333333

00:47:44.080 --> 00:47:46.080 and that this is a way that they  
NOTE Confidence: 0.9313173293333333

00:47:46.080 --> 00:47:47.877 can exercise control and agency  
NOTE Confidence: 0.9313173293333333

00:47:47.877 --> 00:47:49.529 when they're otherwise powerless.  
NOTE Confidence: 0.9313173293333333

00:47:49.530 --> 00:47:51.984 And that's OK that that that's  
NOTE Confidence: 0.9313173293333333

00:47:51.984 --> 00:47:54.180 not necessarily a bad thing.  
NOTE Confidence: 0.9313173293333333

00:47:54.180 --> 00:47:55.538 And I'll skip to the last one,  
NOTE Confidence: 0.9313173293333333

00:47:55.540 --> 00:47:57.692 which is to work with our hospitals to  
NOTE Confidence: 0.9313173293333333

00:47:57.692 --> 00:47:59.358 develop formal guides and education,  
NOTE Confidence: 0.9313173293333333

00:47:59.360 --> 00:48:01.536 and so far in in our first and  
NOTE Confidence: 0.9313173293333333

00:48:01.536 --> 00:48:03.928 in our current physician study,

NOTE Confidence: 0.931317329333333  
00:48:03.930 --> 00:48:06.186 most hospitals do not have a  
NOTE Confidence: 0.931317329333333  
00:48:06.186 --> 00:48:07.690 lot in this area,  
NOTE Confidence: 0.931317329333333  
00:48:07.690 --> 00:48:09.839 and particularly no one yet has told  
NOTE Confidence: 0.931317329333333  
00:48:09.839 --> 00:48:11.947 me about anything to help families  
NOTE Confidence: 0.931317329333333  
00:48:11.947 --> 00:48:13.822 with crowdfunding ethics and the  
NOTE Confidence: 0.931317329333333  
00:48:13.822 --> 00:48:15.319 privacy concerns around that.  
NOTE Confidence: 0.931317329333333  
00:48:15.320 --> 00:48:16.676 So if you have any resources,  
NOTE Confidence: 0.931317329333333  
00:48:16.680 --> 00:48:18.619 I'd be very interested to see them,  
NOTE Confidence: 0.931317329333333  
00:48:18.620 --> 00:48:21.194 but especially around how to evaluate  
NOTE Confidence: 0.931317329333333  
00:48:21.194 --> 00:48:22.910 the credibility of information  
NOTE Confidence: 0.931317329333333  
00:48:22.976 --> 00:48:25.056 online and spot that information.  
NOTE Confidence: 0.931317329333333  
00:48:25.060 --> 00:48:27.090 And even how to take advantage of  
NOTE Confidence: 0.931317329333333  
00:48:27.090 --> 00:48:29.301 the good parts about what's online  
NOTE Confidence: 0.931317329333333  
00:48:29.301 --> 00:48:30.997 because families didn't necessarily  
NOTE Confidence: 0.931317329333333  
00:48:30.997 --> 00:48:33.359 know this when they started out.  
NOTE Confidence: 0.931317329333333

00:48:33.360 --> 00:48:33.922 And finally,  
NOTE Confidence: 0.9313173293333333

00:48:33.922 --> 00:48:36.170 I want to just circle back in my  
NOTE Confidence: 0.9313173293333333

00:48:36.232 --> 00:48:38.941 last couple of slides to the very  
NOTE Confidence: 0.9313173293333333

00:48:38.941 --> 00:48:40.500 public disagreements because they  
NOTE Confidence: 0.9313173293333333

00:48:40.500 --> 00:48:42.510 think this is a really important  
NOTE Confidence: 0.9313173293333333

00:48:42.510 --> 00:48:44.830 point that when disagreements truly  
NOTE Confidence: 0.9313173293333333

00:48:44.830 --> 00:48:47.305 go viral and become interesting  
NOTE Confidence: 0.9313173293333333

00:48:47.305 --> 00:48:49.270 to the larger public,  
NOTE Confidence: 0.9313173293333333

00:48:49.270 --> 00:48:51.260 often driven by social media,  
NOTE Confidence: 0.9313173293333333

00:48:51.260 --> 00:48:52.646 it does become about more than  
NOTE Confidence: 0.9313173293333333

00:48:52.646 --> 00:48:54.120 the interests of the individual,  
NOTE Confidence: 0.9313173293333333

00:48:54.120 --> 00:48:55.467 patient or family.  
NOTE Confidence: 0.9313173293333333

00:48:55.467 --> 00:48:57.712 And really about public trust  
NOTE Confidence: 0.9313173293333333

00:48:57.712 --> 00:48:59.789 in hospitals and Pediatrics.  
NOTE Confidence: 0.9313173293333333

00:48:59.790 --> 00:49:01.230 And I think then we,  
NOTE Confidence: 0.9313173293333333

00:49:01.230 --> 00:49:03.158 as hospitals and organizations.

NOTE Confidence: 0.931317329333333

00:49:03.158 --> 00:49:06.050 Have a responsibility to respond in

NOTE Confidence: 0.875860843571429

00:49:06.131 --> 00:49:07.499 a more nuanced way,

NOTE Confidence: 0.875860843571429

00:49:07.500 --> 00:49:09.759 and so I would add one more thing to

NOTE Confidence: 0.875860843571429

00:49:09.759 --> 00:49:11.920 this list of how we should respond,

NOTE Confidence: 0.875860843571429

00:49:11.920 --> 00:49:14.304 which is that we really need to disrupt

NOTE Confidence: 0.875860843571429

00:49:14.304 --> 00:49:16.120 adverse aerial reasoning or framing,

NOTE Confidence: 0.875860843571429

00:49:16.120 --> 00:49:18.748 or the idea that it's Google

NOTE Confidence: 0.875860843571429

00:49:18.748 --> 00:49:20.500 against the medical degree,

NOTE Confidence: 0.875860843571429

00:49:20.500 --> 00:49:22.360 because that's not what most families

NOTE Confidence: 0.875860843571429

00:49:22.360 --> 00:49:24.200 are doing when they go online,

NOTE Confidence: 0.875860843571429

00:49:24.200 --> 00:49:25.268 even when they disagree.

NOTE Confidence: 0.875860843571429

00:49:25.268 --> 00:49:26.603 And even when those disagreements

NOTE Confidence: 0.875860843571429

00:49:26.603 --> 00:49:27.700 are really entrenched,

NOTE Confidence: 0.875860843571429

00:49:27.700 --> 00:49:29.814 it's not that people are confusing these,

NOTE Confidence: 0.875860843571429

00:49:29.820 --> 00:49:30.796 it's that they don't

NOTE Confidence: 0.875860843571429

00:49:30.796 --> 00:49:32.016 necessarily trust us right away,  
NOTE Confidence: 0.875860843571429

00:49:32.020 --> 00:49:33.840 and we need to work with them to build up.  
NOTE Confidence: 0.875860843571429

00:49:33.840 --> 00:49:36.424 Trust, so I would scrap that one come  
NOTE Confidence: 0.875860843571429

00:49:36.424 --> 00:49:39.258 from our approach and try to find  
NOTE Confidence: 0.875860843571429

00:49:39.258 --> 00:49:41.368 ways that work more collaboratively  
NOTE Confidence: 0.875860843571429

00:49:41.370 --> 00:49:44.261 and that don't pick us as healthcare  
NOTE Confidence: 0.875860843571429

00:49:44.261 --> 00:49:45.980 providers against social media,  
NOTE Confidence: 0.875860843571429

00:49:45.980 --> 00:49:48.370 but working together to get  
NOTE Confidence: 0.875860843571429

00:49:48.370 --> 00:49:49.804 better health outcomes.  
NOTE Confidence: 0.875860843571429

00:49:49.810 --> 00:49:51.030 I'm gonna stop there.  
NOTE Confidence: 0.875860843571429

00:49:51.030 --> 00:49:53.968 That was one of my better timing on talks.  
NOTE Confidence: 0.875860843571429

00:49:53.970 --> 00:49:55.458 Come and take questions.  
NOTE Confidence: 0.89468118

00:49:56.660 --> 00:49:58.052 Thank you so much,  
NOTE Confidence: 0.89468118

00:49:58.052 --> 00:49:59.944 Doctor Trousseau Brown, that's terrific.  
NOTE Confidence: 0.89468118

00:49:59.944 --> 00:50:02.476 There was a lot of really  
NOTE Confidence: 0.89468118

00:50:02.476 --> 00:50:03.503 interesting things in there.

NOTE Confidence: 0.89468118

00:50:03.503 --> 00:50:04.910 I would invite everybody to reach out

NOTE Confidence: 0.89468118

00:50:04.955 --> 00:50:06.209 through the Q&A for your questions

NOTE Confidence: 0.89468118

00:50:06.209 --> 00:50:07.570 and I'll moderate the conversation.

NOTE Confidence: 0.89468118

00:50:07.570 --> 00:50:10.066 I'll present your questions to me,

NOTE Confidence: 0.89468118

00:50:10.070 --> 00:50:12.500 but I want to start with with a question

NOTE Confidence: 0.89468118

00:50:12.500 --> 00:50:15.643 that's been that's been on my mind,

NOTE Confidence: 0.89468118

00:50:15.643 --> 00:50:17.190 and I think a lot of people's

NOTE Confidence: 0.89468118

00:50:17.251 --> 00:50:18.436 minds for a long time.

NOTE Confidence: 0.89468118

00:50:18.440 --> 00:50:20.250 And it's a fascinating psychological

NOTE Confidence: 0.89468118

00:50:20.250 --> 00:50:22.710 phenomenon that I don't really understand,

NOTE Confidence: 0.89468118

00:50:22.710 --> 00:50:24.500 but I think it's become, of course,

NOTE Confidence: 0.89468118

00:50:24.500 --> 00:50:26.300 with regard to the vaccine with

NOTE Confidence: 0.89468118

00:50:26.300 --> 00:50:27.720 the resident COVID vaccine.

NOTE Confidence: 0.89468118

00:50:27.720 --> 00:50:28.772 It's a big issue,

NOTE Confidence: 0.89468118

00:50:28.772 --> 00:50:31.229 but it's not just about the COVID vaccine.

NOTE Confidence: 0.89468118

00:50:31.230 --> 00:50:33.246 I've been fascinated to see time  
NOTE Confidence: 0.89468118

00:50:33.246 --> 00:50:35.285 and again that there's a family  
NOTE Confidence: 0.89468118

00:50:35.285 --> 00:50:37.504 that has a physician for years that  
NOTE Confidence: 0.89468118

00:50:37.504 --> 00:50:39.658 they've had a good relationship with,  
NOTE Confidence: 0.89468118

00:50:39.660 --> 00:50:42.738 and then they read something online  
NOTE Confidence: 0.89468118

00:50:42.740 --> 00:50:45.106 and they actually trust that more than  
NOTE Confidence: 0.89468118

00:50:45.106 --> 00:50:47.498 they trust this physician with whom  
NOTE Confidence: 0.89468118

00:50:47.498 --> 00:50:49.688 they've enjoyed a good relationship.  
NOTE Confidence: 0.89468118

00:50:49.690 --> 00:50:50.570 Can you speak to that?  
NOTE Confidence: 0.89468118

00:50:50.570 --> 00:50:51.880 Why that might be reviewed,  
NOTE Confidence: 0.89468118

00:50:51.880 --> 00:50:53.224 made the same observation.  
NOTE Confidence: 0.89468118

00:50:53.224 --> 00:50:53.560 Sometimes  
NOTE Confidence: 0.965810493333333

00:50:53.720 --> 00:50:56.936 I have made the same observation.  
NOTE Confidence: 0.965810493333333

00:50:56.940 --> 00:50:59.502 And I I don't know that there's  
NOTE Confidence: 0.965810493333333

00:50:59.502 --> 00:51:02.079 just one answer for some families.  
NOTE Confidence: 0.965810493333333

00:51:02.080 --> 00:51:03.800 I've looked back critically on

NOTE Confidence: 0.9658104933333333  
00:51:03.800 --> 00:51:05.520 on my relationship with them,  
NOTE Confidence: 0.9658104933333333  
00:51:05.520 --> 00:51:07.626 and this is really speaking from  
NOTE Confidence: 0.9658104933333333  
00:51:07.626 --> 00:51:09.916 personal experience and said, you know,  
NOTE Confidence: 0.9658104933333333  
00:51:09.916 --> 00:51:13.017 I think the trust was very situational.  
NOTE Confidence: 0.9658104933333333  
00:51:13.020 --> 00:51:15.386 I don't know that they ever trusted  
NOTE Confidence: 0.9658104933333333  
00:51:15.386 --> 00:51:17.580 me completely or across the board,  
NOTE Confidence: 0.9658104933333333  
00:51:17.580 --> 00:51:18.780 or that the you know,  
NOTE Confidence: 0.9658104933333333  
00:51:18.780 --> 00:51:21.174 there's a lot of different ways we can trust  
NOTE Confidence: 0.9658104933333333  
00:51:21.174 --> 00:51:23.546 we can trust a specific recommendation,  
NOTE Confidence: 0.9658104933333333  
00:51:23.550 --> 00:51:25.332 or we can trust a person  
NOTE Confidence: 0.9658104933333333  
00:51:25.332 --> 00:51:26.930 across the board to give.  
NOTE Confidence: 0.9658104933333333  
00:51:26.930 --> 00:51:27.426 Any recommendation,  
NOTE Confidence: 0.9658104933333333  
00:51:27.426 --> 00:51:29.410 and as I've looked at some of these,  
NOTE Confidence: 0.9658104933333333  
00:51:29.410 --> 00:51:31.210 I have specifically thinking of one  
NOTE Confidence: 0.9658104933333333  
00:51:31.210 --> 00:51:33.521 that a patient that came in well after  
NOTE Confidence: 0.9658104933333333

00:51:33.521 --> 00:51:35.590 her cancer therapy and we are her mom,  
NOTE Confidence: 0.9658104933333333

00:51:35.590 --> 00:51:37.326 wants it to tell me all about masking  
NOTE Confidence: 0.9658104933333333

00:51:37.326 --> 00:51:38.969 and how it was going to kill us.  
NOTE Confidence: 0.9658104933333333

00:51:38.970 --> 00:51:41.378 And then that led into the vaccine and  
NOTE Confidence: 0.9658104933333333

00:51:41.378 --> 00:51:43.888 how she doesn't believe any of that.  
NOTE Confidence: 0.9658104933333333

00:51:43.890 --> 00:51:45.390 She doesn't believe that vaccines don't  
NOTE Confidence: 0.9658104933333333

00:51:45.390 --> 00:51:46.959 have these really late side effects,  
NOTE Confidence: 0.9658104933333333

00:51:46.960 --> 00:51:48.985 and I thought I can't believe they let me  
NOTE Confidence: 0.9658104933333333

00:51:48.985 --> 00:51:50.929 give this child chemotherapy like that.  
NOTE Confidence: 0.9658104933333333

00:51:50.930 --> 00:51:53.080 That's an incredibly trusting act,  
NOTE Confidence: 0.9658104933333333

00:51:53.080 --> 00:51:55.871 but I look back and I think yeah,  
NOTE Confidence: 0.9658104933333333

00:51:55.871 --> 00:51:58.277 they trusted me to an extent.  
NOTE Confidence: 0.9658104933333333

00:51:58.280 --> 00:52:00.456 But they also checked a lot of what  
NOTE Confidence: 0.9658104933333333

00:52:00.456 --> 00:52:02.750 I said with their online sources,  
NOTE Confidence: 0.9658104933333333

00:52:02.750 --> 00:52:05.361 and it just happens that in that  
NOTE Confidence: 0.9658104933333333

00:52:05.361 --> 00:52:07.824 case we were aligned and now

NOTE Confidence: 0.9658104933333333

00:52:07.824 --> 00:52:10.183 we're not aligned and they have so

NOTE Confidence: 0.9658104933333333

00:52:10.183 --> 00:52:12.600 many more sources of information.

NOTE Confidence: 0.9658104933333333

00:52:12.600 --> 00:52:14.376 People who they had an ongoing

NOTE Confidence: 0.9658104933333333

00:52:14.376 --> 00:52:16.244 relationship with in those years where

NOTE Confidence: 0.9658104933333333

00:52:16.244 --> 00:52:18.116 I was only seeing them sporadically,

NOTE Confidence: 0.9658104933333333

00:52:18.120 --> 00:52:19.800 but I think that's winning out.

NOTE Confidence: 0.9658104933333333

00:52:19.800 --> 00:52:21.440 So sometimes I think that's what it is.

NOTE Confidence: 0.9658104933333333

00:52:21.440 --> 00:52:24.607 I I think that that I may have felt

NOTE Confidence: 0.9658104933333333

00:52:24.607 --> 00:52:27.036 there was more of a trusting relationship

NOTE Confidence: 0.9658104933333333

00:52:27.036 --> 00:52:28.960 there when it was really very.

NOTE Confidence: 0.9658104933333333

00:52:28.960 --> 00:52:31.780 Very situationally specific trust to me,

NOTE Confidence: 0.9658104933333333

00:52:31.780 --> 00:52:35.680 treating and curing their child's disease.

NOTE Confidence: 0.9658104933333333

00:52:35.680 --> 00:52:38.056 Another theory that has been floated,

NOTE Confidence: 0.9658104933333333

00:52:38.060 --> 00:52:39.313 and I think this holds up when

NOTE Confidence: 0.9658104933333333

00:52:39.313 --> 00:52:40.618 I look back on some families,

NOTE Confidence: 0.9658104933333333

00:52:40.620 --> 00:52:42.500 is the idea that when we meet people

NOTE Confidence: 0.9658104933333333

00:52:42.500 --> 00:52:44.645 at a point of critical illness they

NOTE Confidence: 0.9658104933333333

00:52:44.645 --> 00:52:46.828 need someone to trust and so they

NOTE Confidence: 0.9658104933333333

00:52:46.828 --> 00:52:48.634 may have trusted us and that this

NOTE Confidence: 0.9658104933333333

00:52:48.634 --> 00:52:50.580 may go for the situations in the

NOTE Confidence: 0.9658104933333333

00:52:50.580 --> 00:52:52.728 nick you and they pick you and

NOTE Confidence: 0.9658104933333333

00:52:52.728 --> 00:52:54.565 oncology trusting in the moment of

NOTE Confidence: 0.9658104933333333

00:52:54.565 --> 00:52:56.411 crisis because you need someone to

NOTE Confidence: 0.9658104933333333

00:52:56.411 --> 00:52:58.037 keep you afloat through this while

NOTE Confidence: 0.9658104933333333

00:52:58.037 --> 00:52:59.709 your child is critically ill.

NOTE Confidence: 0.9658104933333333

00:52:59.710 --> 00:53:01.275 But now we're not really

NOTE Confidence: 0.9658104933333333

00:53:01.275 --> 00:53:02.527 talking about critical illness.

NOTE Confidence: 0.9658104933333333

00:53:02.530 --> 00:53:04.000 We're not talking about something

NOTE Confidence: 0.9658104933333333

00:53:04.000 --> 00:53:06.239 that we can see and touch in the

NOTE Confidence: 0.9658104933333333

00:53:06.239 --> 00:53:07.905 way that we can see our child.

NOTE Confidence: 0.9658104933333333

00:53:07.910 --> 00:53:09.166 Sick in the ICU?

NOTE Confidence: 0.9658104933333333  
00:53:09.166 --> 00:53:10.736 We're talking about a disease  
NOTE Confidence: 0.9658104933333333  
00:53:10.736 --> 00:53:12.747 that still has not touched a lot  
NOTE Confidence: 0.9658104933333333  
00:53:12.747 --> 00:53:14.967 of people or not touched as many  
NOTE Confidence: 0.9658104933333333  
00:53:14.967 --> 00:53:17.103 people as the numbers would suggest,  
NOTE Confidence: 0.9658104933333333  
00:53:17.110 --> 00:53:18.340 and that that's where that's  
NOTE Confidence: 0.9658104933333333  
00:53:18.340 --> 00:53:19.324 coming from that this.  
NOTE Confidence: 0.9658104933333333  
00:53:19.330 --> 00:53:21.290 This doesn't have that level of urgency  
NOTE Confidence: 0.9658104933333333  
00:53:21.290 --> 00:53:23.288 and the way those decisions did.  
NOTE Confidence: 0.9658104933333333  
00:53:23.290 --> 00:53:24.156 So again,  
NOTE Confidence: 0.9658104933333333  
00:53:24.156 --> 00:53:26.754 families can defer to social media  
NOTE Confidence: 0.9658104933333333  
00:53:26.760 --> 00:53:29.707 and the last one is this idea  
NOTE Confidence: 0.9658104933333333  
00:53:29.707 --> 00:53:31.980 that social media is just more  
NOTE Confidence: 0.9658104933333333  
00:53:31.980 --> 00:53:33.830 powerful than us right now.  
NOTE Confidence: 0.9658104933333333  
00:53:33.830 --> 00:53:35.912 And I think that goes back  
NOTE Confidence: 0.9658104933333333  
00:53:35.912 --> 00:53:37.300 to medicine and physicians  
NOTE Confidence: 0.963900664375

00:53:37.372 --> 00:53:39.340 not having figured out how to.  
NOTE Confidence: 0.963900664375

00:53:39.340 --> 00:53:40.520 Harness it for good.  
NOTE Confidence: 0.963900664375

00:53:40.520 --> 00:53:42.698 Not not having figured out how to  
NOTE Confidence: 0.963900664375

00:53:42.698 --> 00:53:44.408 use it to disseminate expertise  
NOTE Confidence: 0.963900664375

00:53:44.408 --> 00:53:46.666 as effectively as people are using  
NOTE Confidence: 0.963900664375

00:53:46.666 --> 00:53:48.326 it to disseminate misinformation.  
NOTE Confidence: 0.939926689666667

00:53:49.840 --> 00:53:51.680 And then I guess is to some extent  
NOTE Confidence: 0.939926689666667

00:53:51.680 --> 00:53:53.977 to a significance that on us and the  
NOTE Confidence: 0.939926689666667

00:53:53.977 --> 00:53:56.200 challenge to us if that third possibility  
NOTE Confidence: 0.939926689666667

00:53:56.200 --> 00:53:58.475 is at least part of the problem.  
NOTE Confidence: 0.939926689666667

00:53:58.480 --> 00:54:00.532 I mean, I do think that people tend to  
NOTE Confidence: 0.939926689666667

00:54:00.532 --> 00:54:02.446 believe what they see in print things that  
NOTE Confidence: 0.939926689666667

00:54:02.446 --> 00:54:04.418 are in print center carry some authority.  
NOTE Confidence: 0.939926689666667

00:54:04.418 --> 00:54:07.248 It used to be if it was in print.  
NOTE Confidence: 0.939926689666667

00:54:07.250 --> 00:54:07.864 Not entirely,  
NOTE Confidence: 0.939926689666667

00:54:07.864 --> 00:54:10.013 but to a greater extent than now.

NOTE Confidence: 0.939926689666667  
00:54:10.020 --> 00:54:11.875 Somebody who knew something largely  
NOTE Confidence: 0.939926689666667  
00:54:11.875 --> 00:54:13.359 was responsible for writing,  
NOTE Confidence: 0.939926689666667  
00:54:13.360 --> 00:54:14.116 and now if it was in,  
NOTE Confidence: 0.939926689666667  
00:54:14.120 --> 00:54:15.495 you know the National Enquirer  
NOTE Confidence: 0.939926689666667  
00:54:15.495 --> 00:54:16.870 as opposed to Time magazine.  
NOTE Confidence: 0.939926689666667  
00:54:16.870 --> 00:54:17.920 It might have been something different,  
NOTE Confidence: 0.939926689666667  
00:54:17.920 --> 00:54:20.308 but the reality is now,  
NOTE Confidence: 0.939926689666667  
00:54:20.308 --> 00:54:21.568 of course anybody and everybody  
NOTE Confidence: 0.939926689666667  
00:54:21.568 --> 00:54:22.878 can put something in print  
NOTE Confidence: 0.939926689666667  
00:54:22.880 --> 00:54:25.016 at a moment's notice and do,  
NOTE Confidence: 0.939926689666667  
00:54:25.020 --> 00:54:27.309 and and it's very hard to tell  
NOTE Confidence: 0.939926689666667  
00:54:27.309 --> 00:54:28.670 whether you're hearing from,  
NOTE Confidence: 0.939926689666667  
00:54:28.670 --> 00:54:30.800 you know, a brilliant hematologist  
NOTE Confidence: 0.939926689666667  
00:54:30.800 --> 00:54:32.930 oncologist from from State University,  
NOTE Confidence: 0.939926689666667  
00:54:32.930 --> 00:54:34.478 New York, or just somebody who  
NOTE Confidence: 0.939926689666667

00:54:34.478 --> 00:54:36.378 once had a cousin who had cancer,  
NOTE Confidence: 0.939926689666667

00:54:36.380 --> 00:54:38.200 and therefore has an opinion about it.  
NOTE Confidence: 0.939926689666667

00:54:38.200 --> 00:54:39.396 Uhm, is they all?  
NOTE Confidence: 0.939926689666667

00:54:39.396 --> 00:54:41.580 All those the font looks the same,  
NOTE Confidence: 0.939926689666667

00:54:41.580 --> 00:54:42.332 you know?  
NOTE Confidence: 0.939926689666667

00:54:42.332 --> 00:54:42.708 Yeah,  
NOTE Confidence: 0.835665422857143

00:54:42.720 --> 00:54:45.177 that's the thing that font really does.  
NOTE Confidence: 0.835665422857143

00:54:45.180 --> 00:54:48.680 The websites look equally professional.  
NOTE Confidence: 0.835665422857143

00:54:48.680 --> 00:54:50.870 Even when and and I think for all of us,  
NOTE Confidence: 0.835665422857143

00:54:50.870 --> 00:54:52.894 how do you know a website is not  
NOTE Confidence: 0.835665422857143

00:54:52.894 --> 00:54:54.859 a valid source of information?  
NOTE Confidence: 0.835665422857143

00:54:54.860 --> 00:54:56.827 It's this very subtle feeling that things  
NOTE Confidence: 0.835665422857143

00:54:56.827 --> 00:55:00.221 are just a little bit off after a career  
NOTE Confidence: 0.835665422857143

00:55:00.221 --> 00:55:03.106 of looking at scientific information,  
NOTE Confidence: 0.835665422857143

00:55:03.110 --> 00:55:04.950 can we expect families to  
NOTE Confidence: 0.835665422857143

00:55:04.950 --> 00:55:06.422 do the same immediately?

NOTE Confidence: 0.835665422857143

00:55:06.430 --> 00:55:08.229 I think no, no, not without more

NOTE Confidence: 0.835665422857143

00:55:08.229 --> 00:55:10.000 support and more education from us.

NOTE Confidence: 0.8061986125

00:55:10.950 --> 00:55:12.898 Yeah, that's that's, uh,

NOTE Confidence: 0.8061986125

00:55:12.898 --> 00:55:14.846 that's that's well put,

NOTE Confidence: 0.8061986125

00:55:14.850 --> 00:55:17.950 I'm gonna invite the folks in the to

NOTE Confidence: 0.8061986125

00:55:17.950 --> 00:55:20.950 submit any questions through the Q&A.

NOTE Confidence: 0.8061986125

00:55:20.950 --> 00:55:22.216 Do you have another one here?

NOTE Confidence: 0.8061986125

00:55:22.220 --> 00:55:26.119 Which is you had mentioned that you

NOTE Confidence: 0.8061986125

00:55:26.119 --> 00:55:28.710 discouraged families from Googling?

NOTE Confidence: 0.8061986125

00:55:28.710 --> 00:55:29.758 Excuse me, you discourage

NOTE Confidence: 0.8061986125

00:55:29.758 --> 00:55:30.544 physicians from Googling.

NOTE Confidence: 0.8061986125

00:55:30.550 --> 00:55:32.200 Families don't look up the

NOTE Confidence: 0.8061986125

00:55:32.200 --> 00:55:33.520 families on the Internet.

NOTE Confidence: 0.8061986125

00:55:33.520 --> 00:55:35.500 Could you explain why?

NOTE Confidence: 0.884173203

00:55:36.600 --> 00:55:39.606 Yeah, I think it's on on

NOTE Confidence: 0.884173203

00:55:39.606 --> 00:55:41.610 one level it's asking.  
NOTE Confidence: 0.884173203

00:55:41.610 --> 00:55:43.520 It's inviting a difficult situation  
NOTE Confidence: 0.884173203

00:55:43.520 --> 00:55:46.211 that we won't know how to resolve  
NOTE Confidence: 0.884173203

00:55:46.211 --> 00:55:48.335 or be able to resolve ethically.  
NOTE Confidence: 0.884173203

00:55:48.340 --> 00:55:50.556 And this for me this has been mostly  
NOTE Confidence: 0.884173203

00:55:50.556 --> 00:55:52.718 asked in the context of teenagers,  
NOTE Confidence: 0.884173203

00:55:52.720 --> 00:55:55.570 so my colleagues who either do a lot of AY  
NOTE Confidence: 0.884173203

00:55:55.639 --> 00:55:58.489 oncology or do adolescent medicine asking,  
NOTE Confidence: 0.884173203

00:55:58.490 --> 00:56:01.207 is it OK to look up my patient or  
NOTE Confidence: 0.884173203

00:56:01.207 --> 00:56:04.060 I did look up my patient and I saw  
NOTE Confidence: 0.884173203

00:56:04.152 --> 00:56:07.068 him drinking or her posting about?  
NOTE Confidence: 0.884173203

00:56:07.070 --> 00:56:08.243 A sexual encounter,  
NOTE Confidence: 0.884173203

00:56:08.243 --> 00:56:09.807 and now I'm wondering,  
NOTE Confidence: 0.884173203

00:56:09.810 --> 00:56:11.778 do I bring this up in my visit  
NOTE Confidence: 0.884173203

00:56:11.778 --> 00:56:14.477 and and I think that that is very  
NOTE Confidence: 0.884173203

00:56:14.477 --> 00:56:15.901 invasive of patients privacy.

NOTE Confidence: 0.884173203

00:56:15.910 --> 00:56:17.674 There there is not an expectation

NOTE Confidence: 0.884173203

00:56:17.674 --> 00:56:19.544 or there shouldn't be an expectation

NOTE Confidence: 0.884173203

00:56:19.544 --> 00:56:21.144 of privacy on the Internet,

NOTE Confidence: 0.884173203

00:56:21.150 --> 00:56:23.103 but that doesn't mean there's not an

NOTE Confidence: 0.884173203

00:56:23.103 --> 00:56:24.455 expectation that your doctor won't

NOTE Confidence: 0.884173203

00:56:24.455 --> 00:56:26.770 look you up on purpose and read about you.

NOTE Confidence: 0.884173203

00:56:26.770 --> 00:56:29.031 And I think that expectation for most

NOTE Confidence: 0.884173203

00:56:29.031 --> 00:56:31.839 families or for most patients is still there,

NOTE Confidence: 0.884173203

00:56:31.840 --> 00:56:33.590 that when they're sharing online,

NOTE Confidence: 0.884173203

00:56:33.590 --> 00:56:35.102 they're not thinking their

NOTE Confidence: 0.884173203

00:56:35.102 --> 00:56:37.640 physicians are going to look it up.

NOTE Confidence: 0.884173203

00:56:37.640 --> 00:56:39.288 And I I think we should honor that.

NOTE Confidence: 0.884173203

00:56:39.290 --> 00:56:40.211 It's it's not.

NOTE Confidence: 0.884173203

00:56:40.211 --> 00:56:42.053 It's not that everyone posting online

NOTE Confidence: 0.884173203

00:56:42.053 --> 00:56:44.076 should be aware that this could happen,

NOTE Confidence: 0.884173203

00:56:44.080 --> 00:56:46.897 but I think we should honor the idea that

NOTE Confidence: 0.884173203

00:56:46.897 --> 00:56:49.425 unless they invite us into those spaces,

NOTE Confidence: 0.884173203

00:56:49.430 --> 00:56:50.660 they're not expecting us to

NOTE Confidence: 0.884173203

00:56:50.660 --> 00:56:51.644 be in those spaces.

NOTE Confidence: 0.944610978333333

00:56:53.090 --> 00:56:55.736 Thank you someone, just very quickly.

NOTE Confidence: 0.944610978333333

00:56:55.740 --> 00:56:56.796 Karen, if you could help us

NOTE Confidence: 0.944610978333333

00:56:56.796 --> 00:56:57.940 with this on the chat side,

NOTE Confidence: 0.944610978333333

00:56:57.940 --> 00:56:59.525 someone who just asked again

NOTE Confidence: 0.944610978333333

00:56:59.525 --> 00:57:01.709 for the CME code to text on.

NOTE Confidence: 0.944610978333333

00:57:01.710 --> 00:57:04.518 If you have the number that folks should

NOTE Confidence: 0.944610978333333

00:57:04.518 --> 00:57:07.556 text it to in order to get CME credit

NOTE Confidence: 0.944610978333333

00:57:07.556 --> 00:57:10.140 just to remind you another question.

NOTE Confidence: 0.944610978333333

00:57:10.140 --> 00:57:11.710 Related to privacy you had,

NOTE Confidence: 0.944610978333333

00:57:11.710 --> 00:57:14.716 you had spoken about the child's

NOTE Confidence: 0.944610978333333

00:57:14.716 --> 00:57:17.319 right to privacy and parents

NOTE Confidence: 0.944610978333333

00:57:17.319 --> 00:57:19.564 a tendency to tend parents.

NOTE Confidence: 0.944610978333333

00:57:19.564 --> 00:57:21.449 Tendency to share overshare information.

NOTE Confidence: 0.944610978333333

00:57:21.450 --> 00:57:22.554 And, of course,

NOTE Confidence: 0.944610978333333

00:57:22.554 --> 00:57:24.718 this problem predates this problem.

NOTE Confidence: 0.944610978333333

00:57:24.718 --> 00:57:26.622 Predates social media parents

NOTE Confidence: 0.944610978333333

00:57:26.622 --> 00:57:28.680 tendency to overshare their

NOTE Confidence: 0.944610978333333

00:57:28.680 --> 00:57:30.369 children private information,

NOTE Confidence: 0.944610978333333

00:57:30.370 --> 00:57:32.692 but what practical advice can you

NOTE Confidence: 0.944610978333333

00:57:32.692 --> 00:57:34.691 give physicians that they might

NOTE Confidence: 0.944610978333333

00:57:34.691 --> 00:57:36.971 share with parents to help them

NOTE Confidence: 0.944610978333333

00:57:36.971 --> 00:57:38.523 understand about the child's

NOTE Confidence: 0.944610978333333

00:57:38.523 --> 00:57:40.545 right to a need for privacy?

NOTE Confidence: 0.855758997

00:57:41.450 --> 00:57:42.840 Yeah, I think it's something

NOTE Confidence: 0.855758997

00:57:42.840 --> 00:57:44.230 that in in our study,

NOTE Confidence: 0.855758997

00:57:44.230 --> 00:57:46.358 a lot of parents just haven't thought

NOTE Confidence: 0.855758997

00:57:46.358 --> 00:57:48.462 about it and and partly that's

NOTE Confidence: 0.855758997

00:57:48.462 --> 00:57:50.347 specific to the serious illness  
NOTE Confidence: 0.855758997

00:57:50.347 --> 00:57:52.254 context that people were focused  
NOTE Confidence: 0.855758997

00:57:52.254 --> 00:57:54.438 on getting enough support to get  
NOTE Confidence: 0.855758997

00:57:54.438 --> 00:57:56.376 through today and from some of them  
NOTE Confidence: 0.855758997

00:57:56.376 --> 00:57:58.747 they were not at all sure that their  
NOTE Confidence: 0.855758997

00:57:58.747 --> 00:58:00.637 children would live to be adults,  
NOTE Confidence: 0.855758997

00:58:00.640 --> 00:58:02.565 so that was less of a concern,  
NOTE Confidence: 0.855758997

00:58:02.570 --> 00:58:04.478 but a lot of them just.  
NOTE Confidence: 0.855758997

00:58:04.480 --> 00:58:06.100 Their children had good prognosis,  
NOTE Confidence: 0.855758997

00:58:06.100 --> 00:58:08.032 they just hadn't really thought about  
NOTE Confidence: 0.855758997

00:58:08.032 --> 00:58:10.336 it because they were so focused on now  
NOTE Confidence: 0.855758997

00:58:10.336 --> 00:58:12.491 and so just the idea that we should  
NOTE Confidence: 0.855758997

00:58:12.491 --> 00:58:14.156 be talking through with parents,  
NOTE Confidence: 0.855758997

00:58:14.160 --> 00:58:15.188 and it doesn't necessarily  
NOTE Confidence: 0.855758997

00:58:15.188 --> 00:58:16.473 mean that it's the physician.  
NOTE Confidence: 0.855758997

00:58:16.480 --> 00:58:18.106 It might be a member of

NOTE Confidence: 0.855758997

00:58:18.106 --> 00:58:18.919 the psychosocial team,

NOTE Confidence: 0.855758997

00:58:18.920 --> 00:58:22.358 someone else in a outpatient clinic.

NOTE Confidence: 0.855758997

00:58:22.360 --> 00:58:24.604 It might be part of anticipatory

NOTE Confidence: 0.855758997

00:58:24.604 --> 00:58:26.100 guidance for general pediatricians,

NOTE Confidence: 0.855758997

00:58:26.100 --> 00:58:28.180 but just what are you putting on line?

NOTE Confidence: 0.855758997

00:58:28.180 --> 00:58:30.094 Are you thinking about how this

NOTE Confidence: 0.855758997

00:58:30.094 --> 00:58:31.820 might affect your child's future?

NOTE Confidence: 0.855758997

00:58:31.820 --> 00:58:33.128 What will happen when they go

NOTE Confidence: 0.855758997

00:58:33.128 --> 00:58:34.489 to apply to college or get it?

NOTE Confidence: 0.855758997

00:58:34.490 --> 00:58:35.790 Job and someone Google's them,

NOTE Confidence: 0.855758997

00:58:35.790 --> 00:58:37.995 which we know admissions officers

NOTE Confidence: 0.855758997

00:58:37.995 --> 00:58:40.656 are doing and spite in spite of my

NOTE Confidence: 0.855758997

00:58:40.656 --> 00:58:42.221 feelings on people's privacy and

NOTE Confidence: 0.855758997

00:58:42.221 --> 00:58:43.846 not searching out those things.

NOTE Confidence: 0.855758997

00:58:43.850 --> 00:58:46.419 We know admissions officers are doing it.

NOTE Confidence: 0.855758997

00:58:46.420 --> 00:58:48.282 Do you think it might hurt your  
NOTE Confidence: 0.855758997

00:58:48.282 --> 00:58:50.004 child for that medical information  
NOTE Confidence: 0.855758997

00:58:50.004 --> 00:58:51.736 to be readily accessible?  
NOTE Confidence: 0.855758997

00:58:51.740 --> 00:58:53.406 We think about that all the time.  
NOTE Confidence: 0.855758997

00:58:53.410 --> 00:58:55.786 With privacy around disability and genetics,  
NOTE Confidence: 0.855758997

00:58:55.790 --> 00:58:57.505 but I don't think parents are thinking  
NOTE Confidence: 0.855758997

00:58:57.505 --> 00:58:59.294 about it unless we bring it up and  
NOTE Confidence: 0.855758997

00:58:59.294 --> 00:59:00.890 talk it through with them in that way.  
NOTE Confidence: 0.855758997

00:59:00.890 --> 00:59:02.577 And I think that's why I think  
NOTE Confidence: 0.855758997

00:59:02.577 --> 00:59:03.639 it's important that we do.  
NOTE Confidence: 0.855758997

00:59:03.640 --> 00:59:06.466 I would ultimately, if I was.  
NOTE Confidence: 0.855758997

00:59:06.470 --> 00:59:08.070 Advocating or had more time  
NOTE Confidence: 0.855758997

00:59:08.070 --> 00:59:09.030 to advocate legislatively?  
NOTE Confidence: 0.855758997

00:59:09.030 --> 00:59:11.158 I think there should be some legal  
NOTE Confidence: 0.855758997

00:59:11.158 --> 00:59:13.518 protections for kids about the amount of  
NOTE Confidence: 0.855758997

00:59:13.518 --> 00:59:15.690 information that parents can put online,

NOTE Confidence: 0.855758997

00:59:15.690 --> 00:59:16.670 but until we have that,

NOTE Confidence: 0.855758997

00:59:16.670 --> 00:59:19.289 I think the best we can do is educate

NOTE Confidence: 0.855758997

00:59:19.289 --> 00:59:20.880 families and hope that they'll

NOTE Confidence: 0.855758997

00:59:20.880 --> 00:59:22.505 weigh the benefits to themselves,

NOTE Confidence: 0.855758997

00:59:22.510 --> 00:59:23.220 which they're.

NOTE Confidence: 0.855758997

00:59:23.220 --> 00:59:25.350 They're a real psychosocial benefits there,

NOTE Confidence: 0.855758997

00:59:25.350 --> 00:59:26.770 but hopefully they can weigh

NOTE Confidence: 0.855758997

00:59:26.770 --> 00:59:28.190 those benefits against the future

NOTE Confidence: 0.855758997

00:59:28.237 --> 00:59:29.197 risks for their kids.

NOTE Confidence: 0.905036651851851

00:59:29.920 --> 00:59:32.008 You know it's so much that this will

NOTE Confidence: 0.905036651851851

00:59:32.008 --> 00:59:34.395 put me and it's so much a part of what

NOTE Confidence: 0.905036651851851

00:59:34.395 --> 00:59:36.726 we do is is to try and help parents.

NOTE Confidence: 0.905036651851851

00:59:36.730 --> 00:59:38.632 Take the Longview and this is

NOTE Confidence: 0.905036651851851

00:59:38.632 --> 00:59:40.330 really what it's about is it?

NOTE Confidence: 0.905036651851851

00:59:40.330 --> 00:59:42.226 Is that I seek some reassurance

NOTE Confidence: 0.905036651851851

00:59:42.226 --> 00:59:44.469 about today but take the wrong take.  
NOTE Confidence: 0.905036651851851

00:59:44.470 --> 00:59:46.143 The Longview about that picture or about  
NOTE Confidence: 0.905036651851851

00:59:46.143 --> 00:59:47.908 that thing you write about your child.  
NOTE Confidence: 0.905036651851851

00:59:47.910 --> 00:59:49.266 But someday that kid is going  
NOTE Confidence: 0.905036651851851

00:59:49.266 --> 00:59:51.014 to have to face his friends and  
NOTE Confidence: 0.905036651851851

00:59:51.014 --> 00:59:52.586 his friends all knowing this or  
NOTE Confidence: 0.905036651851851

00:59:52.586 --> 00:59:54.208 that about his medical history,  
NOTE Confidence: 0.905036651851851

00:59:54.210 --> 00:59:55.645 that he might not want people to  
NOTE Confidence: 0.905036651851851

00:59:55.645 --> 00:59:57.109 know or his future employers,  
NOTE Confidence: 0.905036651851851

00:59:57.110 --> 00:59:59.580 or anybody else you know.  
NOTE Confidence: 0.905036651851851

00:59:59.580 --> 01:00:01.095 That that taking the Longview  
NOTE Confidence: 0.905036651851851

01:00:01.095 --> 01:00:02.890 that's that's part of our job,  
NOTE Confidence: 0.905036651851851

01:00:02.890 --> 01:00:05.240 hopefully supposedly not always easy,  
NOTE Confidence: 0.905036651851851

01:00:05.240 --> 01:00:06.759 particularly when parents are in a crisis,  
NOTE Confidence: 0.905036651851851

01:00:06.760 --> 01:00:07.371 understandably.  
NOTE Confidence: 0.905036651851851

01:00:07.371 --> 01:00:10.426 Uhm, some other questions here.

NOTE Confidence: 0.905036651851851  
01:00:10.430 --> 01:00:12.376 What is the best course of action?  
NOTE Confidence: 0.905036651851851  
01:00:12.380 --> 01:00:14.662 If a patient goes onto a social  
NOTE Confidence: 0.905036651851851  
01:00:14.662 --> 01:00:16.518 media platform and attacks a  
NOTE Confidence: 0.905036651851851  
01:00:16.518 --> 01:00:18.130 doctor or medical practice,  
NOTE Confidence: 0.905036651851851  
01:00:18.130 --> 01:00:19.706 what's the best course  
NOTE Confidence: 0.905036651851851  
01:00:19.706 --> 01:00:21.676 of action in that case?  
NOTE Confidence: 0.905036651851851  
01:00:21.680 --> 01:00:22.320 Yeah,  
NOTE Confidence: 0.78010496  
01:00:22.330 --> 01:00:27.442 uh, it depends a little bit on the details,  
NOTE Confidence: 0.78010496  
01:00:27.450 --> 01:00:31.097 so the individual attack from one patient  
NOTE Confidence: 0.78010496  
01:00:31.097 --> 01:00:34.479 is probably something that is best ignored.  
NOTE Confidence: 0.78010496  
01:00:34.480 --> 01:00:36.632 So like on on Yelp and some of  
NOTE Confidence: 0.78010496  
01:00:36.632 --> 01:00:38.702 these other websites where every  
NOTE Confidence: 0.78010496  
01:00:38.702 --> 01:00:40.646 everybody gets negative reviews,  
NOTE Confidence: 0.78010496  
01:00:40.650 --> 01:00:44.030 there's sometimes really quite hostile.  
NOTE Confidence: 0.78010496  
01:00:44.030 --> 01:00:45.926 And I had several years ago.  
NOTE Confidence: 0.78010496

01:00:45.930 --> 01:00:48.233 Dunno, very informal study of physicians on  
NOTE Confidence: 0.78010496

01:00:48.233 --> 01:00:50.699 Facebook and ask them how they respond and.  
NOTE Confidence: 0.78010496

01:00:50.700 --> 01:00:51.705 Lots of people.  
NOTE Confidence: 0.78010496

01:00:51.705 --> 01:00:53.380 I'm not necessarily not really  
NOTE Confidence: 0.78010496

01:00:53.380 --> 01:00:55.690 endorsing this, but lots of people get.  
NOTE Confidence: 0.78010496

01:00:55.690 --> 01:00:57.766 They sold this it better reviews.  
NOTE Confidence: 0.78010496

01:00:57.770 --> 01:00:59.840 So their response to that is to ask patients  
NOTE Confidence: 0.78010496

01:00:59.840 --> 01:01:01.717 that they have a good rapport with two.  
NOTE Confidence: 0.78010496

01:01:01.720 --> 01:01:03.495 Hey, please give me a  
NOTE Confidence: 0.78010496

01:01:03.495 --> 01:01:04.860 review which I think is OK,  
NOTE Confidence: 0.78010496

01:01:04.860 --> 01:01:07.004 but then some of them had friends and  
NOTE Confidence: 0.78010496

01:01:07.004 --> 01:01:08.579 family posting fake reviews which.  
NOTE Confidence: 0.78010496

01:01:08.580 --> 01:01:11.508 Little bit less OK.  
NOTE Confidence: 0.78010496

01:01:11.510 --> 01:01:14.450 So that's one for the individual attack,  
NOTE Confidence: 0.78010496

01:01:14.450 --> 01:01:16.961 I think where it's on a much larger scale  
NOTE Confidence: 0.78010496

01:01:16.961 --> 01:01:19.127 like these conflicts that go viral.

NOTE Confidence: 0.78010496

01:01:19.130 --> 01:01:21.566 Those are the ones where we really

NOTE Confidence: 0.78010496

01:01:21.566 --> 01:01:23.829 need a nuanced and coordinated.

NOTE Confidence: 0.78010496

01:01:23.830 --> 01:01:25.811 And really I think there were Brianna

NOTE Confidence: 0.78010496

01:01:25.811 --> 01:01:27.449 more uses a sophisticated organizational

NOTE Confidence: 0.78010496

01:01:27.449 --> 01:01:30.361 response of the kind that a lot of

NOTE Confidence: 0.78010496

01:01:30.421 --> 01:01:32.556 hospitals have not been very good at,

NOTE Confidence: 0.78010496

01:01:32.560 --> 01:01:34.756 or the response at the hospital

NOTE Confidence: 0.78010496

01:01:34.756 --> 01:01:37.199 level or the practice level has

NOTE Confidence: 0.78010496

01:01:37.199 --> 01:01:39.469 generally been to ignore disengaged.

NOTE Confidence: 0.78010496

01:01:39.470 --> 01:01:42.068 And I say we cannot comment.

NOTE Confidence: 0.78010496

01:01:42.070 --> 01:01:42.427 Matt,

NOTE Confidence: 0.78010496

01:01:42.427 --> 01:01:44.926 and in that I cannot comment on

NOTE Confidence: 0.78010496

01:01:44.926 --> 01:01:47.858 that space leaves a lot of room for

NOTE Confidence: 0.78010496

01:01:47.858 --> 01:01:50.180 the bad information for the attack.

NOTE Confidence: 0.78010496

01:01:50.180 --> 01:01:53.246 For the misinformation to continue to spread.

NOTE Confidence: 0.78010496

01:01:53.250 --> 01:01:55.329 So I do think it's important with  
NOTE Confidence: 0.78010496

01:01:55.329 --> 01:01:57.290 those conflicts that while respecting  
NOTE Confidence: 0.78010496

01:01:57.290 --> 01:01:58.808 the patients confidentiality,  
NOTE Confidence: 0.78010496

01:01:58.810 --> 01:02:01.570 we do what we can to educate people  
NOTE Confidence: 0.78010496

01:02:01.570 --> 01:02:03.776 and to engage within our local  
NOTE Confidence: 0.78010496

01:02:03.776 --> 01:02:05.960 community to try to engage our local  
NOTE Confidence: 0.78010496

01:02:06.025 --> 01:02:08.029 communities in those conversations  
NOTE Confidence: 0.78010496

01:02:08.030 --> 01:02:10.472 and ultimately to make it all  
NOTE Confidence: 0.78010496

01:02:10.472 --> 01:02:12.100 learning experience for everyone.  
NOTE Confidence: 0.78010496

01:02:12.100 --> 01:02:14.290 Just letting.  
NOTE Confidence: 0.78010496

01:02:14.290 --> 01:02:16.096 I think sometimes we fall back on.  
NOTE Confidence: 0.78010496

01:02:16.100 --> 01:02:17.766 We can't say anything when it's not  
NOTE Confidence: 0.78010496

01:02:17.766 --> 01:02:19.539 really true that we can't say anything.  
NOTE Confidence: 0.78010496

01:02:19.540 --> 01:02:22.044 We may not be able to comment on  
NOTE Confidence: 0.78010496

01:02:22.044 --> 01:02:24.450 the specific details of the patient  
NOTE Confidence: 0.78010496

01:02:24.450 --> 01:02:26.580 involved in whatever was posted,

NOTE Confidence: 0.78010496  
01:02:26.580 --> 01:02:28.442 but we might be able to say  
NOTE Confidence: 0.78010496  
01:02:28.442 --> 01:02:29.500 something generally about hey.  
NOTE Confidence: 0.78010496  
01:02:29.500 --> 01:02:31.060 How do we approach cases like  
NOTE Confidence: 0.78010496  
01:02:31.060 --> 01:02:31.840 those in general,  
NOTE Confidence: 0.78010496  
01:02:31.840 --> 01:02:33.256 or why do we approach those?  
NOTE Confidence: 0.78010496  
01:02:33.260 --> 01:02:35.066 Or if it's somebody who's just  
NOTE Confidence: 0.78010496  
01:02:35.066 --> 01:02:36.655 really angry about the current  
NOTE Confidence: 0.78010496  
01:02:36.655 --> 01:02:38.569 weights in our pediatric Ed like  
NOTE Confidence: 0.78010496  
01:02:38.569 --> 01:02:40.379 we were talking about earlier?  
NOTE Confidence: 0.78010496  
01:02:40.380 --> 01:02:41.540 Educating our community about  
NOTE Confidence: 0.78010496  
01:02:41.540 --> 01:02:43.280 what's going on with COVID and  
NOTE Confidence: 0.78010496  
01:02:43.330 --> 01:02:44.490 why those weights exist.  
NOTE Confidence: 0.78010496  
01:02:44.490 --> 01:02:46.434 All of those are important things to do.  
NOTE Confidence: 0.97145768  
01:02:49.120 --> 01:02:52.208 Thank you very much.  
NOTE Confidence: 0.97145768  
01:02:52.210 --> 01:02:53.842 That takes care of the questions  
NOTE Confidence: 0.97145768

01:02:53.842 --> 01:02:55.746 I want to then offer you Amy.  
NOTE Confidence: 0.97145768

01:02:55.746 --> 01:02:58.169 Any final words you want to share with us?  
NOTE Confidence: 0.97145768

01:02:58.170 --> 01:03:00.480 This is, this has been really helpful  
NOTE Confidence: 0.97145768

01:03:00.480 --> 01:03:03.028 both in terms of framing the problem.  
NOTE Confidence: 0.97145768

01:03:03.030 --> 01:03:05.032 The way you categorize the various ways  
NOTE Confidence: 0.97145768

01:03:05.032 --> 01:03:07.248 that this can hurt us and importantly,  
NOTE Confidence: 0.97145768

01:03:07.250 --> 01:03:08.834 the various ways we can make  
NOTE Confidence: 0.97145768

01:03:08.834 --> 01:03:10.470 it better or make it worse.  
NOTE Confidence: 0.97145768

01:03:10.470 --> 01:03:12.122 And you know, in some of those  
NOTE Confidence: 0.97145768

01:03:12.122 --> 01:03:13.848 responses where we could make it worse,  
NOTE Confidence: 0.97145768

01:03:13.850 --> 01:03:14.636 I'm thinking, yeah,  
NOTE Confidence: 0.97145768

01:03:14.636 --> 01:03:16.208 I've seen that done I've I've  
NOTE Confidence: 0.97145768

01:03:16.208 --> 01:03:17.366 heard that done, you know,  
NOTE Confidence: 0.97145768

01:03:17.366 --> 01:03:19.150 I I I'm familiar with that because of course,  
NOTE Confidence: 0.97145768

01:03:19.150 --> 01:03:21.778 the physicians and nurses that are.  
NOTE Confidence: 0.97145768

01:03:21.780 --> 01:03:24.783 The the recipients of sometimes the bad

NOTE Confidence: 0.97145768

01:03:24.783 --> 01:03:26.838 press on Facebook certainly are human

NOTE Confidence: 0.97145768

01:03:26.838 --> 01:03:28.374 beings and and take that personally.

NOTE Confidence: 0.97145768

01:03:28.380 --> 01:03:30.068 But there's still ways to make it better,

NOTE Confidence: 0.97145768

01:03:30.070 --> 01:03:31.366 even not just for our patients

NOTE Confidence: 0.97145768

01:03:31.366 --> 01:03:32.014 and their parents,

NOTE Confidence: 0.97145768

01:03:32.020 --> 01:03:34.297 but for ourselves and how we respond to that.

NOTE Confidence: 0.97145768

01:03:34.300 --> 01:03:36.460 So I think that's some of this stuff was

NOTE Confidence: 0.97145768

01:03:36.460 --> 01:03:38.400 really insightful and and very helpful.

NOTE Confidence: 0.97145768

01:03:38.400 --> 01:03:40.368 And and try and you know the the

NOTE Confidence: 0.97145768

01:03:40.368 --> 01:03:42.596 Internet can help us or hurt us in so

NOTE Confidence: 0.97145768

01:03:42.596 --> 01:03:44.601 many different ways and and social media

NOTE Confidence: 0.97145768

01:03:44.601 --> 01:03:46.437 can just the Internet before social

NOTE Confidence: 0.97145768

01:03:46.440 --> 01:03:48.528 media was a thing and I can recall

NOTE Confidence: 0.97145768

01:03:48.528 --> 01:03:50.860 talking to talking to parents and saying,

NOTE Confidence: 0.97145768

01:03:50.860 --> 01:03:52.428 well, you know in this situation this.

NOTE Confidence: 0.97145768

01:03:52.430 --> 01:03:55.190 Because of my clinical gig,  
NOTE Confidence: 0.97145768

01:03:55.190 --> 01:03:56.702 I'm talking to parents who are expecting  
NOTE Confidence: 0.97145768

01:03:56.702 --> 01:03:58.110 a child who's going to be critically  
NOTE Confidence: 0.97145768

01:03:58.110 --> 01:04:00.070 ill and I said well in situations like this.  
NOTE Confidence: 0.97145768

01:04:00.070 --> 01:04:02.006 You know, some people say such and such,  
NOTE Confidence: 0.97145768

01:04:02.010 --> 01:04:02.854 and they say, yeah,  
NOTE Confidence: 0.97145768

01:04:02.854 --> 01:04:04.120 but you've said such and such,  
NOTE Confidence: 0.97145768

01:04:04.120 --> 01:04:05.050 and I think I don't  
NOTE Confidence: 0.97145768

01:04:05.050 --> 01:04:05.794 remember telling you that.  
NOTE Confidence: 0.97145768

01:04:05.800 --> 01:04:06.288 And they said, well,  
NOTE Confidence: 0.97145768

01:04:06.288 --> 01:04:07.109 yeah, we read it.  
NOTE Confidence: 0.97145768

01:04:07.109 --> 01:04:08.507 You know yesterday and of course,  
NOTE Confidence: 0.97145768

01:04:08.510 --> 01:04:09.980 so everything any of us have ever  
NOTE Confidence: 0.97145768

01:04:09.980 --> 01:04:11.497 written is out there for parents who  
NOTE Confidence: 0.97145768

01:04:11.497 --> 01:04:13.329 want to have the energy to look for it,  
NOTE Confidence: 0.97145768

01:04:13.330 --> 01:04:15.808 and the savvy to look for it.

NOTE Confidence: 0.97145768  
01:04:15.810 --> 01:04:16.458 And of course,  
NOTE Confidence: 0.97145768  
01:04:16.458 --> 01:04:18.330 social media is made this so much easier.  
NOTE Confidence: 0.97145768  
01:04:18.330 --> 01:04:19.716 So the same folks who might not  
NOTE Confidence: 0.97145768  
01:04:19.716 --> 01:04:21.470 be able to access the article that  
NOTE Confidence: 0.97145768  
01:04:21.470 --> 01:04:23.138 you wrote in Journal of Pediatrics.  
NOTE Confidence: 0.97145768  
01:04:23.140 --> 01:04:25.051 May nevertheless be able to access the  
NOTE Confidence: 0.97145768  
01:04:25.051 --> 01:04:26.711 opinion of someone who posted something  
NOTE Confidence: 0.97145768  
01:04:26.711 --> 01:04:28.552 on Facebook or in a support group,  
NOTE Confidence: 0.97145768  
01:04:28.560 --> 01:04:30.784 so it's actually made it easier to find  
NOTE Confidence: 0.97145768  
01:04:30.784 --> 01:04:32.898 the things that might be less helpful.  
NOTE Confidence: 0.97145768  
01:04:32.900 --> 01:04:33.842 But in fairness,  
NOTE Confidence: 0.97145768  
01:04:33.842 --> 01:04:35.098 it's entirely possible that  
NOTE Confidence: 0.97145768  
01:04:35.098 --> 01:04:36.308 someone discovers something in  
NOTE Confidence: 0.97145768  
01:04:36.308 --> 01:04:37.616 one of these social media sites.  
NOTE Confidence: 0.97145768  
01:04:37.620 --> 01:04:40.329 That's important that that error that was  
NOTE Confidence: 0.97145768

01:04:40.329 --> 01:04:43.579 made by us that someone else picks up,  
NOTE Confidence: 0.97145768

01:04:43.580 --> 01:04:45.150 so we shouldn't discount the  
NOTE Confidence: 0.97145768

01:04:45.150 --> 01:04:47.260 possibility that it could help somebody,  
NOTE Confidence: 0.97145768

01:04:47.260 --> 01:04:49.116 but we all kind of live in fear  
NOTE Confidence: 0.97145768

01:04:49.116 --> 01:04:50.559 of the harm it can do,  
NOTE Confidence: 0.97145768

01:04:50.560 --> 01:04:51.844 and the disinformation that  
NOTE Confidence: 0.97145768

01:04:51.844 --> 01:04:53.414 can be that can be spread.  
NOTE Confidence: 0.97145768

01:04:53.414 --> 01:04:54.569 This has been really helpful,  
NOTE Confidence: 0.97145768

01:04:54.570 --> 01:04:56.598 so that's enough of me talking.  
NOTE Confidence: 0.97145768

01:04:56.600 --> 01:04:58.877 I want to see come now let me just  
NOTE Confidence: 0.97145768

01:04:58.877 --> 01:05:01.067 say actually before we sign off,  
NOTE Confidence: 0.97145768

01:05:01.070 --> 01:05:03.808 I do in fact have another comment  
NOTE Confidence: 0.97145768

01:05:03.808 --> 01:05:06.776 here by a friend who says that  
NOTE Confidence: 0.97145768

01:05:06.776 --> 01:05:08.855 language rights are civil rights  
NOTE Confidence: 0.97145768

01:05:08.855 --> 01:05:11.213 and made clear in the Civil  
NOTE Confidence: 0.920254239166667

01:05:11.298 --> 01:05:13.318 Rights Act 64 and EO 13166.

NOTE Confidence: 0.920254239166667  
01:05:13.318 --> 01:05:15.442 I wonder how the language barriers  
NOTE Confidence: 0.920254239166667  
01:05:15.442 --> 01:05:17.412 and cultural issues between parents  
NOTE Confidence: 0.920254239166667  
01:05:17.412 --> 01:05:19.402 and the dominant culture and  
NOTE Confidence: 0.920254239166667  
01:05:19.402 --> 01:05:21.682 children who tend to embrace this  
NOTE Confidence: 0.920254239166667  
01:05:21.682 --> 01:05:24.088 culture and parents can be resolved.  
NOTE Confidence: 0.920254239166667  
01:05:24.088 --> 01:05:27.210 Should I read that one more time?  
NOTE Confidence: 0.920254239166667  
01:05:27.210 --> 01:05:29.275 I wonder how the language barriers and  
NOTE Confidence: 0.920254239166667  
01:05:29.275 --> 01:05:30.843 the cultural issues between parents  
NOTE Confidence: 0.920254239166667  
01:05:30.843 --> 01:05:32.733 and the dominant culture and children  
NOTE Confidence: 0.920254239166667  
01:05:32.733 --> 01:05:34.579 who tend to embrace this culture  
NOTE Confidence: 0.920254239166667  
01:05:34.579 --> 01:05:36.319 and parents that can be resolved.  
NOTE Confidence: 0.84327579  
01:05:38.490 --> 01:05:39.766 Yeah, that it's intra.  
NOTE Confidence: 0.84327579  
01:05:39.766 --> 01:05:41.361 It's interesting in the in  
NOTE Confidence: 0.84327579  
01:05:41.361 --> 01:05:43.188 the setting of social media,  
NOTE Confidence: 0.84327579  
01:05:43.190 --> 01:05:45.840 because in some ways it's.  
NOTE Confidence: 0.84327579

01:05:45.840 --> 01:05:47.615 I don't subscribe fully to  
NOTE Confidence: 0.84327579

01:05:47.615 --> 01:05:48.325 generational differences,  
NOTE Confidence: 0.84327579

01:05:48.330 --> 01:05:51.194 but it is generational as much as cultural.  
NOTE Confidence: 0.84327579

01:05:51.200 --> 01:05:53.184 And when I we we have a partnership  
NOTE Confidence: 0.84327579

01:05:53.184 --> 01:05:54.643 with Kenya with the Children's  
NOTE Confidence: 0.84327579

01:05:54.643 --> 01:05:56.153 Hospital in Kenya and before  
NOTE Confidence: 0.84327579

01:05:56.153 --> 01:05:58.169 COVID I was able to spend a month  
NOTE Confidence: 0.84327579

01:05:58.169 --> 01:06:00.223 a year there and I asked them  
NOTE Confidence: 0.84327579

01:06:00.223 --> 01:06:02.509 these questions and they had much  
NOTE Confidence: 0.84327579

01:06:02.509 --> 01:06:05.414 the culturally a very different  
NOTE Confidence: 0.84327579

01:06:05.414 --> 01:06:07.854 approach to treatment disagreements.  
NOTE Confidence: 0.84327579

01:06:07.860 --> 01:06:09.676 Very, very different system  
NOTE Confidence: 0.84327579

01:06:09.676 --> 01:06:11.946 in terms of what happens.  
NOTE Confidence: 0.84327579

01:06:11.950 --> 01:06:13.858 If a parent refuses, but also,  
NOTE Confidence: 0.84327579

01:06:13.860 --> 01:06:15.240 how often does a parent reviews  
NOTE Confidence: 0.84327579

01:06:15.240 --> 01:06:16.160 most of the time.

NOTE Confidence: 0.84327579

01:06:16.160 --> 01:06:18.140 They do whatever the doctor says,

NOTE Confidence: 0.84327579

01:06:18.140 --> 01:06:20.192 but at the same time everyone

NOTE Confidence: 0.84327579

01:06:20.192 --> 01:06:22.398 still had the experience of parents

NOTE Confidence: 0.84327579

01:06:22.398 --> 01:06:24.714 checking social media and asking about

NOTE Confidence: 0.84327579

01:06:24.714 --> 01:06:26.948 things they found on social media.

NOTE Confidence: 0.84327579

01:06:26.950 --> 01:06:29.194 It was something that has really

NOTE Confidence: 0.84327579

01:06:29.194 --> 01:06:31.094 started to transcend the world

NOTE Confidence: 0.84327579

01:06:31.094 --> 01:06:33.116 and be part of global culture.

NOTE Confidence: 0.84327579

01:06:33.120 --> 01:06:34.401 And so I don't know that that's

NOTE Confidence: 0.84327579

01:06:34.401 --> 01:06:35.200 an answer to that.

NOTE Confidence: 0.84327579

01:06:35.200 --> 01:06:36.940 Just that I think when I

NOTE Confidence: 0.84327579

01:06:36.940 --> 01:06:38.100 think about social media,

NOTE Confidence: 0.84327579

01:06:38.100 --> 01:06:40.360 I'm surprised that there aren't

NOTE Confidence: 0.84327579

01:06:40.360 --> 01:06:41.716 more cultural differences.

NOTE Confidence: 0.84327579

01:06:41.720 --> 01:06:44.400 I think in some way it's it's a

NOTE Confidence: 0.84327579

01:06:44.400 --> 01:06:46.031 phenomenon that is overtaking  
NOTE Confidence: 0.84327579

01:06:46.031 --> 01:06:47.357 the entire world.  
NOTE Confidence: 0.84327579

01:06:47.360 --> 01:06:48.970 Even as it plays out a little  
NOTE Confidence: 0.84327579

01:06:48.970 --> 01:06:50.197 bit differently in different  
NOTE Confidence: 0.84327579

01:06:50.197 --> 01:06:51.640 cultural scenarios situations.  
NOTE Confidence: 0.965808005

01:06:53.280 --> 01:06:56.650 Thank you. Any final thoughts for Sammy?  
NOTE Confidence: 0.854372025555555

01:06:57.150 --> 01:06:59.733 I think my my final thought is just engaged.  
NOTE Confidence: 0.854372025555555

01:06:59.740 --> 01:07:01.826 I think we as a profession in  
NOTE Confidence: 0.854372025555555

01:07:01.826 --> 01:07:03.684 healthcare have put off engaging with  
NOTE Confidence: 0.854372025555555

01:07:03.684 --> 01:07:06.211 social media for too long and I think  
NOTE Confidence: 0.854372025555555

01:07:06.211 --> 01:07:08.443 we've we've left that vacuum for  
NOTE Confidence: 0.854372025555555

01:07:08.443 --> 01:07:10.216 misinformation like we were discussing.  
NOTE Confidence: 0.854372025555555

01:07:10.216 --> 01:07:12.512 So a take home point with everyone  
NOTE Confidence: 0.854372025555555

01:07:12.512 --> 01:07:14.836 would be to to try engaging if you're  
NOTE Confidence: 0.854372025555555

01:07:14.836 --> 01:07:16.788 not already with social media and and  
NOTE Confidence: 0.854372025555555

01:07:16.788 --> 01:07:18.810 figure out how to do that effectively,

NOTE Confidence: 0.8543720255555555  
01:07:18.810 --> 01:07:20.960 how to have those conversations.  
NOTE Confidence: 0.9383765533333333  
01:07:22.460 --> 01:07:24.964 Very good thank you, thank you so very  
NOTE Confidence: 0.9383765533333333  
01:07:24.964 --> 01:07:26.768 much for this excellent talk and I  
NOTE Confidence: 0.9383765533333333  
01:07:26.768 --> 01:07:28.568 want to thank everyone who joined us  
NOTE Confidence: 0.9383765533333333  
01:07:28.568 --> 01:07:30.134 tonight and we look forward to seeing  
NOTE Confidence: 0.9383765533333333  
01:07:30.134 --> 01:07:31.740 you folks again in a couple weeks.  
NOTE Confidence: 0.9383765533333333  
01:07:31.740 --> 01:07:33.645 You can find the schedule  
NOTE Confidence: 0.9383765533333333  
01:07:33.645 --> 01:07:35.092 biomedical ethics at yale.edu,  
NOTE Confidence: 0.9383765533333333  
01:07:35.092 --> 01:07:37.206 but for tonight we had a terrific  
NOTE Confidence: 0.9383765533333333  
01:07:37.206 --> 01:07:38.918 conversation and learned a great deal.  
NOTE Confidence: 0.9383765533333333  
01:07:38.920 --> 01:07:40.340 And for that we thank  
NOTE Confidence: 0.9383765533333333  
01:07:40.340 --> 01:07:41.476 Doctor Amy Caruso Brown.  
NOTE Confidence: 0.9383765533333333  
01:07:41.480 --> 01:07:43.209 We hope to have you back sometime  
NOTE Confidence: 0.9383765533333333  
01:07:43.209 --> 01:07:45.157 and hope to have you back in  
NOTE Confidence: 0.9383765533333333  
01:07:45.157 --> 01:07:46.309 person because there's a.  
NOTE Confidence: 0.9383765533333333

01:07:46.310 --> 01:07:46.832 There's some good.

NOTE Confidence: 0.9383765533333333

01:07:46.832 --> 01:07:48.235 There's some good food to be had in

NOTE Confidence: 0.9383765533333333

01:07:48.235 --> 01:07:49.379 New Haven and we'd like to meet you

NOTE Confidence: 0.9383765533333333

01:07:49.379 --> 01:07:50.725 and get a chance to share it with you.

NOTE Confidence: 0.93583957

01:07:51.360 --> 01:07:53.416 That would be great. I would love that.

NOTE Confidence: 0.93583957

01:07:53.420 --> 01:07:56.000 Have a wonderful night everyone goodnight.