

WEBVTT

NOTE duration:"00:26:16.386000"

NOTE language:en-us

NOTE Confidence: 0.913709282875061

00:00:00.020 --> 00:00:13.850 We have 2 great speakers today our first week will be persona. Non and she's from the Pediatrics Department here and he monk and she's going to be talking about improving end of life care quality for children with cancer.

NOTE Confidence: 0.83118349313736

00:00:17.400 --> 00:00:27.800 Have to lower that microphone to fit me. Thanks everyone for the opportunity to present my work at Cancer Center grand rounds.

NOTE Confidence: 0.941518843173981

00:00:28.430 --> 00:00:50.950 So today, I'll share with you a little bit of background on my research and give you a little bit of context on why research on end of life care for children with cancer is important. I'll describe some of the groundwork for my current research and then share with you. The results of a qualitative study in which we explored how to stakeholders define high quality end of life care for children with cancer.

NOTE Confidence: 0.947217106819153

00:00:52.990 --> 00:01:19.910 So, despite a number of advances in treatment for children with cancer over the past couple of decades cancer remains the number one cause of disease related death in children each year, a little over 15,000 children are diagnosed with cancer and 80 to 90% of these children are cured long term, but one out of every 8 children will not survive. Their disease, so this is estimated to be around 1900 children every year who died.

NOTE Confidence: 0.925935804843903

00:01:21.180 --> 00:01:45.740 Whi study end of life care for children with cancer. We know that kids with cancer have limited access to palliative care and Hospice resources and there's really a dearth of empiric data out there. Most studies are plagued by very small sample size and utilized administrative data, which have its limitations in general studies using patient reported outcomes or very scarce.

NOTE Confidence: 0.913184225559235

00:01:46.690 --> 00:02:18.880 One such study conducted by my mentor Joanne Wolf looked at symptom burden in children with advanced cancer and I know that the print is probably a little bit tiny to see but what this indicates on the X axis is symptom problem, so these were all children at multiple centers who reported on their symptoms and what you can see here is that even in an era where we have a lot of therapies for some duh management and access to

palliative care. Children with cancer continue to experience substantial pain and so this.

NOTE Confidence: 0.930811047554016

00:02:18.880 --> 00:02:34.950 This blue bar represents high distress symptoms that cause a great deal of distress and patience, you can see a whole range of symptoms that are highly distressing to children with cancer? What this indicates is that there are substantial room for improvement in care of these children with advanced cancer.

NOTE Confidence: 0.927395343780518

00:02:37.060 --> 00:03:08.270 We previously conducted a study using the pediatric health information system database, which includes data from over 40 US children's hospitals. We looked at over 1200 children across the country with a range of chronic conditions. So children with cancer were included in this cohort, but we're in the only children here in ages 1 to 18 years, who died in the hospital in 2012. What we specifically examined was resource use of the hospital, including hospital days days spent in the intensive care unit and costs of care.

NOTE Confidence: 0.937323331832886

00:03:08.270 --> 00:03:13.300 As well as major medical intervention, so things like mechanical ventilation or operations.

NOTE Confidence: 0.925503790378571

00:03:14.210 --> 00:03:44.900 While the intended purpose of the study was not necessarily to compare children with cancer to the overall cohort. I put these data side by side just to give you a little bit of a sense of how children with cancer compared to other children with serious illness. What you can see is that children with cancers have more frequent admissions to the hospital. Anna higher total number of hospital days in the last year of life and overall. Not surprisingly, also accrue greater hospital costs as a result.

NOTE Confidence: 0.918668985366821

00:03:45.790 --> 00:04:04.180 We looked at care received in the terminal admission or the admission, which these children died, so for children with cancer. What we found was that about 1/4 received some form of technology assistance in this terminal admission so this included placement of tracheostomy tubes or gastrostomy tube to help sustain health status.

NOTE Confidence: 0.910301625728607

00:04:04.790 --> 00:04:07.440 Over 1/3 underwent operations.

NOTE Confidence: 0.92609053850174

00:04:08.070 --> 00:04:17.340 Over half or mechanically ventilated by this admission and 3/4 of children had an unplanned admission that ultimately resulted

in death.

NOTE Confidence: 0.923222184181213

00:04:19.540 --> 00:04:44.080 So we concluded from this national study that children with cancer have a high burden of hospital resource use in the last year of life and that most children. This cohort spend at least 1 month in the hospital in their last year of life, whereas children with cancer spent at least 2 months or longer. Moreover, it appeared that major medical interventions like mechanical ventilation operations are quite frequent in the terminal admission.

NOTE Confidence: 0.932459831237793

00:04:45.600 --> 00:05:06.370 What does the literature say well it turns out that the subsequent literature actually supports these findings in that a majority of children with cancer throughout North America appeared to receive intensive services near the end of life. This includes frequent use of the emergency Department the intensive care unit. The hospital and across the board low rates of referral to Hospice.

NOTE Confidence: 0.951082110404968

00:05:07.020 --> 00:05:18.340 But really the question that remains unanswered is what constitutes overly intense end of life care. We really have no idea about the preferences and values of children and their families.

NOTE Confidence: 0.932886838912964

00:05:19.460 --> 00:05:28.560 So this was the core question driving my research going forward. What really defines high quality or good end of life care for children with cancer.

NOTE Confidence: 0.925069391727448

00:05:30.880 --> 00:06:01.350 So, in order to talk about this further. I'll just share a little bit of background on what we use to measure quality so quality measures as defined by the National Academy and Madison are tools to evaluate health care structure processes and patient preferences with the goal of delivering patient centered or better care measures can be developed by any number of stewards and then are submitted to organizations like the National Quality Forum for endorsement. There are a range of measures in palliative and end of life care that's with this.

NOTE Confidence: 0.917036712169647

00:06:01.350 --> 00:06:20.050 Graphic represents that are mandatorily reported by Hospice agencies, but a lot of these measured and actually are then. Subsequently, Tide to reimbursement. But the vast majority of these measures in Hospice and end of life care are explicitly exclude pediatric age patients.

NOTE Confidence: 0.917224407196045

00:06:20.960 --> 00:06:48.020 So I'll share with you, some adult quality measures in the cancer Contacts and why we have unique considerations for children with cancer so for example, it's generally considered good care to avoid death in the hospital for an adult with advanced cancer, whereas we know from anecdotal evidence and from prior research that patients and parents may prefer in hospital death, either for comfort of the child or respite for the family.

NOTE Confidence: 0.942453622817993

00:06:48.850 --> 00:07:03.690 Similarly, for adults with cancer. It's generally considered good care to enroll in Hospice. At least 3 days. Prior to death. But we know even from our state of Connecticut that Hospice availability or the capacity to care for children may be very limited.

NOTE Confidence: 0.93992418050766

00:07:06.710 --> 00:07:27.700 So we conducted a qualitative study involving a range of stakeholders with two primary objectives. The first was to explore stakeholder priorities in caring for children with cancer near the end of life and then second to examine whether existing quality measures for adults with cancer are relevant to kids.

NOTE Confidence: 0.876700401306152

00:07:29.590 --> 00:07:35.410 This study involved 54 stakeholders across 2 sites both Yale and Dana Farber.

NOTE Confidence: 0.923001646995544

00:07:35.990 --> 00:07:46.870 We started out with two provider focus group, so one with physicians and one with non physician providers last fall and then also conducted a number of interviews over the past year.

NOTE Confidence: 0.921738564968109

00:07:47.550 --> 00:08:21.380 We included 12 brief parents for providers in these 1 on one interviews and then sort of a novel aspect of the study was that we also sought to interview adolescent and young adult patients and parents of children who have advanced cancer. So this was defined as metastatic disease or cancer that had progressed beyond the initial diagnosis or was incurable. I think this really adds a valuable perspective in that a lot of the published literature examines the perspectives of brief parents. It's definitely difficult to engage brief family members in research.

NOTE Confidence: 0.909594297409058

00:08:21.380 --> 00:08:34.550 But in some regards involving a brief parents and talking about the care their child received at the end of life. When the worst is already happened is somewhat easier than talking with a patient or parent, who is facing advanced illness, but hasn't sort of.

NOTE Confidence: 0.911181330680847

00:08:35.190 --> 00:08:38.990 Thought about what the circumstances might be in which they'd like to die.

NOTE Confidence: 0.896914005279541

00:08:41.760 --> 00:08:53.460 Our interviews and focus groups were all audio, recorded transcribed verbatim and inductively coded and then we use grounded theory to analyze the data.

NOTE Confidence: 0.933161854743958

00:08:55.780 --> 00:09:15.260 So just to give you a sense of demographics. This is what qualitative study with a small sample size and we use purposive sampling so we tried to get a range of perspectives trying to include some mothers as well as father's in the study are a range of racial and ethnic backgrounds, an children with a variety of diagnosis.

NOTE Confidence: 0.254722774028778

00:09:16.310 --> 00:09:16.800 But.

NOTE Confidence: 0.921833872795105

00:09:17.930 --> 00:09:31.180 So I'll share with you now some of the recurrent themes that we saw from our qualitative analysis and the ways in which these themes either aligned or didn't align with existing adult quality measures in this context.

NOTE Confidence: 0.940301358699799

00:09:31.830 --> 00:09:55.960 So our participants spoke to us time and again about the importance of direct communication with their child. Only a few brief parents reflected on not wanting to have a conversation with their child about the end of life in part because of age related considerations. But in general. Patients parents and providers alike. All talked about wanting to have developmentally appropriate conversations about what the end of life might look like.

NOTE Confidence: 0.932769536972046

00:09:56.640 --> 00:10:26.540 All of our participants talked about the importance of interdisciplinary team involvement using chemotherapy. It has the opportunity to relieve symptoms honoring family preference for location of death. Whether that be home, or hospital and access to the hospital or emergency department for some aspects of care in all of these cases. These measures are different from what is generally considered good end of life care for adults?

NOTE Confidence: 0.925978302955627

00:10:27.270 --> 00:10:44.030 So for example, in the adult context. Generally, there is a preference to avoid death in the hospital. But we know from our study and I'll share with you. Some specific quotes that attest to this that there are some benefits to being admitted to the hospital.

NOTE Confidence: 0.92432826757431

00:10:45.500 --> 00:10:50.580 A lot of our participants talked about the importance of symptom control specifically pain control.

NOTE Confidence: 0.918697357177734

00:10:51.080 --> 00:11:04.400 Avoiding intensive resuscitation so avoiding mechanical ventilation or CPR at the end of life and then the importance of Hospice referral. Although we did elicit a number of misconceptions about Hospice that I'll share with you.

NOTE Confidence: 0.931147873401642

00:11:07.120 --> 00:11:38.010 So, in regards to direct communication with the child. A number of participants talked about this one. Parent said to us. If the child is coherent. I think that it's really important to hear from the child in regard to their wishes and what they want and a patient, said to us a child might not understand that they're going to die, so I think it's important to explain to them in terms of. They'll understand what's going to happen. I think the takeaway here is that age appropriate anticipatory guidance is clearly very helpful and.

NOTE Confidence: 0.927615106105804

00:11:38.010 --> 00:11:51.480 Not all circumstances will we be able to sort of explain in full what's happening to a child, but there are clearly is value placed on having some sort of communication directly with that child, and not just with the parents.

NOTE Confidence: 0.937400758266449

00:11:53.650 --> 00:12:16.270 Not surprisingly, a number of our participants talked extensively about the importance of an interdisciplinary team, so this included incorporating the input of nursing staff or psychosocial clinicians child life. Even Hospice representatives and you know all of our participants talked about how important that is how everybody has good ideas.

NOTE Confidence: 0.923723042011261

00:12:18.460 --> 00:12:48.750 Interestingly, in terms of chemotherapy near the end of life. Our participants did underscore that they felt that chemotherapy may offer some measure of symptom relief and satisfaction for parents that no stone was left unturned so generally speaking. I think as providers. We have this perception that we don't want to continue to offer enrollment an early phase clinical trials. If it's really clear that this patient is dying, but our participants really said that there may be some utility.

NOTE Confidence: 0.91539478302002

00:12:48.750 --> 00:13:08.880 Weather that's for the coping of the family or for relief of symptoms. So one bereavement when brief parents use me talked about

how for them. There wasn't an option or at least they didn't perceive any other option chemotherapy is what we had to do in order to save my child interesting. Lee it didn't turn out that way. But I don't have any regrets.

NOTE Confidence: 0.929085373878479

00:13:12.170 --> 00:13:46.530 In terms of hospital use near the end of life. I thought this was really interesting in that I think we have a lot of preconceived notions about where people want to die and a lot of adolescent patients talked about not wanting to spend too much time in the hospital. But what are on the whole? What are participants really told us was that there may be some resources available in the hospital that can't be provided at home that a lot of times children have needs that extend beyond what home nursing can provide or what Hospice services at home can provide.

NOTE Confidence: 0.938891410827637

00:13:46.530 --> 00:13:53.850 One brief parent told us personally, I wouldn't have been able to take care of her at home to the extent that she needed to be taken care of.

NOTE Confidence: 0.918156564235687

00:13:54.480 --> 00:14:19.280 A provider told us avoidance of death in the hospital again. I don't think it's a good marker because we have many families who say that they're scared to have their child die at home for either them or for the child or for siblings. They don't want that in the house to be a memory and so again. I think it's a very personal decision, so clearly. The takeaway here is that having the option of hospital use is valued.

NOTE Confidence: 0.890370428562164

00:14:21.530 --> 00:14:44.160 And then in regards to symptom control interesting. Lee all our participants really talk primarily about pain and not about a whole range of other symptoms. But one brief parents said to us. My number one priority is just for her to be comfortable and pain free and then a patient said. You want to keep them out of clay nannina pay play. Skews me where they are comfortable in the last moments of life.

NOTE Confidence: 0.904440820217133

00:14:44.830 --> 00:14:48.920 So clearly assessing an relieving pain is highly important.

NOTE Confidence: 0.89524245262146

00:14:50.380 --> 00:15:09.960 And then in regards to avoidance of intensive resuscitation a provider, said to us avoidance of mechanical ventilation at the end of life is very relevant. It's a temporizing measure a brief parent than said CPR wouldn't be for the child to revive them to be in more pain that would be from a parent who can't let go? I think.

NOTE Confidence: 0.926351964473724

00:15:10.600 --> 00:15:25.950 So with some exceptions, there were a few parents, who talked about how it's really sort of patient or family dependent, but apart from those exceptions in general, participants preferred to avoid CPR or mechanical ventilation if possible.

NOTE Confidence: 0.9204021692276

00:15:29.200 --> 00:16:00.730 And then in regards to Hospice as I was saying earlier. We elicited a number of misconceptions about Hospice so one adolescent patients had to us. I feel like Hospice is a symbol almost of end of life. I don't think it's a place that kids should ever have to experience and this was sort of a recurrent theme throughout that some of our patients and parents had never really been spoken to about Hospice and needed some orientation as to what Hospice is and what it has to offer about half of the brief parents involved in our study actually had utilized Hospice.

NOTE Confidence: 0.918071150779724

00:16:00.730 --> 00:16:02.650 Spoke very positively about it.

NOTE Confidence: 0.940121352672577

00:16:03.170 --> 00:16:24.560 One provider than said I think we're very limited as to Hospice agencies that are comfortable providing for children and I think that Connecticut is a really good example where we have just two hospices across the state that can offer any resources for children and I can count on one hand, the number of nurses who feel comfortable taking care of children who are dying.

NOTE Confidence: 0.919859766960144

00:16:25.290 --> 00:16:39.580 So we have real pediatric limitations in terms of hostas resources so while it may be nice to refer children to Hospice. We can't always guarantee that Hospice services will be received or that families will receive the extent of services that they desire.

NOTE Confidence: 0.931574046611786

00:16:43.050 --> 00:17:03.110 So what we found in our study was that patient and family reported quality measures were clearly very important so this included direct communication with the child involving an interdisciplinary team and controlling symptoms and that we really ought to honor family preferences for location of death.

NOTE Confidence: 0.92904806137085

00:17:04.280 --> 00:17:22.050 Interestingly, there were a number of health care utilization measures that were elicited here, so the importance of offering chemo if used for symptom relief, allowing for hospital or emergency Department visits if there is some benefit in terms of symptom control or respite for the family.

NOTE Confidence: 0.920594096183777

00:17:22.670 --> 00:17:53.240 Facilitating Hospice referral where Hospice resources are available and then avoiding mechanical ventilation or CPR. I think the big challenge here with patient and family reported quality measures is that these data are not consistently reported or collected in any fashion, whereas some of the elements of health care. Utilization can be obtained through administrative databases. There is actually a lot of components here like Hospice, referral that we actually can't.

NOTE Confidence: 0.921274602413177

00:17:53.240 --> 00:17:56.390 Necessarily accurately obtained from an administrative database.

NOTE Confidence: 0.943032741546631

00:17:56.940 --> 00:18:18.140 So this really kind of underscores the importance of having novel tools for collecting. These data whether those tools are natural language processing or development of an instrument that systematically administered. We really don't have any standards in this context for end of life care and don't consistently collect any of these information from our children who have advanced cancer.

NOTE Confidence: 0.916435599327087

00:18:20.890 --> 00:18:40.770 Alright so I moved a little bit more quickly than I anticipated but I'll I just like to acknowledge my amazing mentor ship here and at Dana Farber, an incredible interdisciplinary research team that's really helped us conduct. This research across 2 centers and all the support both at Yale and externally through foundation grants.

NOTE Confidence: 0.765124678611755

00:18:41.830 --> 00:18:45.680 And here in welcome your questions.

NOTE Confidence: 0.861048817634583

00:18:48.080 --> 00:19:20.190 Yeah, so I'll give you a really specific personal example in terms of how health insurance has an impact. So what I'll say is that children with serious illness alot of times they'll have private insurance, but also be eligible for supplemental Medicaid and so when their private insurance stops paying for some component of care oftentimes Medicaid will kick in.

NOTE Confidence: 0.932440340518951

00:19:20.190 --> 00:19:53.400 But just to give a really specific example. We recently took care of a child with advanced glioblastoma in the hospital and after he had been in the hospital for a couple of weeks. I was on the Phone with an insurance company kind of arguing for wanting to keep the child in the hospital. The family wanted to stay in the hospital. This child had a lot of care needs that couldn't be accommodated at home and they didn't feel comfortable

going to a Hospice facility and so you know, I spoke initially with a private insurer then we realized that the patient had supplemental Medicaid insurance that kicked in. But.

NOTE Confidence: 0.940505146980286

00:19:53.400 --> 00:20:05.270 Ultimately, I think that family will be responsible for paying for some component of their in hospital stay. So I think that's a huge limiting factor here, but largely because of this.

NOTE Confidence: 0.916853368282318

00:20:05.780 --> 00:20:15.380 Notion or this assumption that that some of the same care that can be provided in the hospital for someone who is dying can be provided at home and we know that that's not true.

NOTE Confidence: 0.79539543390274

00:20:18.150 --> 00:20:36.130 Is there typically or counseling available for parents or siblings of patients that might help. I'm sure this is very emotionally fraught process and I imagine that it's also somewhat age, dependent verification as to how long.

NOTE Confidence: 0.918984353542328

00:20:36.730 --> 00:21:09.180 Yeah, so we do actually have standards for psychosocial care of children with advanced cancer and most centers around the country have have access to child life specialists social workers or psychologists, the resources are really limited. But every child that are center is assigned a psychosocial clinician as well as you know they engage with child life. Enrollment in Hospice has one added benefit in that there are bereavement services that are offered to families for.

NOTE Confidence: 0.922888219356537

00:21:09.180 --> 00:21:24.190 6 months to a year after the child dies, and that can be accessed by the by the parents by the siblings alot of hospitals around the country don't have formalized bereavement programs or ways to sort of continue to support brief families afterwards.

NOTE Confidence: 0.56280928850174

00:21:26.250 --> 00:21:27.090 Carrie.

NOTE Confidence: 0.761946141719818

00:21:28.670 --> 00:21:31.800 A little bit more about some of the policies.

NOTE Confidence: 0.683157205581665

00:21:32.820 --> 00:21:34.480 For instance in.

NOTE Confidence: 0.18245841562748

00:21:34.980 --> 00:21:35.810 Goals.

NOTE Confidence: 0.872394144535065

00:21:43.030 --> 00:22:10.350 Some of these people are going to be in the hospital or do you want things or I won't restart button or do you want to receive cancer directed therapy our policies a barrier to that for kids in ha so interesting with the advent of the Affordable Care Act. There was a provision for concurrent care for children So what that allows for is concurrent.

NOTE Confidence: 0.915877103805542

00:22:10.890 --> 00:22:41.050 Illness directed therapy an enrollment in Hospice. I think practically speaking, a lot of Hospice agencies do. Still, I think you still have to be sort of within the last 6 months of life estimated and I think that can be really challenging for children because the trajectory of illness can vary and we do have an option for example, at Yale of virtual Hospice where a child can be admitted to the hospital and have sort of the same nursing staff the same attending.

NOTE Confidence: 0.912675023078918

00:22:41.530 --> 00:22:58.960 But we have the addition of a Hospice nurse, what I've heard serve practically speaking about that virtual Hospice option is that virtual Hospice agencies are also selective about who they admit to their Hospice. And so not everyone who necessarily wants Hospice will be admitted because there's costs associated with it.

NOTE Confidence: 0.866734623908997

00:23:01.290 --> 00:23:30.020 Aaron I have a microphone. I'll bring down 'cause. It's hard to hear in this room. So we didn't ask specifically about transfusion. But some bereaved parents, who are enrolled in Hospice talked a lot about transfusions being a reason. They would want to come to the hospital or want to come to the emergency Department because that can't be provided in a Hospice.

NOTE Confidence: 0.869424998760223

00:23:30.840 --> 00:23:35.670 Setting and often can't even be provided necessarily in clinic.

NOTE Confidence: 0.861137628555298

00:23:37.630 --> 00:24:08.880 Yes, thank you. I'm the attitude and the demeanor of the parents affect the child significantly if the parents are distressed or sad or in front of the child. It doesn't help are the parents getting any counseling here at New Haven Hospital do they have access to?

NOTE Confidence: 0.774145841598511

00:24:08.880 --> 00:24:11.240 Psycho social.

NOTE Confidence: 0.930715560913086

00:24:11.770 --> 00:24:42.540 Help like the child right so this was a challenge actually that some parents described in that they had mental health needs and our team is there to support the whole family, but the train. Psycho social clinicians on our team are really intended to support children and siblings. I would think so for parents who are really struggling who needed prescription medications to help with coping or anxiety.

NOTE Confidence: 0.927340686321259

00:24:42.540 --> 00:25:01.040 They had to be referred to outpatient resources and some families reflected on that being very difficult when their child is actively ill or dying having to go outside the hospital for therapy or pay out of pocket for those resources was really challenging and something that was often neglected.

NOTE Confidence: 0.910966753959656

00:25:01.860 --> 00:25:33.310 I'll take a turn. Thank you so much for this talk. I just want to acknowledge for those of us who don't hear these stories a lot. I can only imagine that some of this is overwhelming to hear what the experiences of parents caring for these very sick children as a parent myself just thinking about that, so thank you for bringing this. I think your comments about where patients want to die is really important. So when we make this distinction between adults and children but I would make the argument that many adults.

NOTE Confidence: 0.91751104593277

00:25:33.310 --> 00:26:03.890 Would choose to die in the hospital if they could really understand the trajectory in the care needs that are involved, and for the caregivers to family caregivers too. Sometimes the hospital is the right place and so just to add that to our thinking about how do we think about the best end of life care and what a good Defcon mean to different families? Yeah, I mean? I didn't mention this earlier, but those measures that I described for adult cancer are really hotly contested.

NOTE Confidence: 0.929547429084778

00:26:03.890 --> 00:26:09.140 Not everybody agrees with using those metrics to assess for a good death.

NOTE Confidence: 0.888188123703003

00:26:09.810 --> 00:26:16.390 And in the studies that we're looking at uh when we asked well Americans where they want to die. Most people say at home with the?