From a Trauma and Surgical Lens: Tools for Palliative Care and End-of-Life Management in Adolescents and Young Adults - Pediatric Grand Rounds-9-5-25-Meeting Recording

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◉ **Calderon, Delia** started transcription


Ranch, Daniel 0:06
All right. Good morning. It's 7:30, so we'll get started. Welcome everybody to Pediatric Grand Rounds at UT San Antonio. Had to squeeze in our new branding there. All right. So it's my great pleasure to introduce our two speakers for today.


Smith, Victor Philip 0:15
OK.


Ranch, Daniel 0:23
And I hear some background noise. Sorry, if anyone's logged on who hasn't muted, please do mute your device. Our first speaker is Doctor Victor Smith, and I'm going to fly through these because they have a lot of content to go through. Neonatologist and Medical Director of the NICU Family Support Program and Neonatology Lead of.


Smith, Victor Philip 0:24
It.
It.
It.
Yes.
OK.


Ranch, Daniel 0:43
Our perinatal support care education program. He received his medical degree and completed his Pediatric residency at East Tennessee State University and completed his neonatal perinatal medicine and hospice and palliative medicine fellowships here

at UT Health San Antonio. He HAS joined the faculty in the neonatology and palliative care divisions.

Smith, Victor Philip 0:54
Are.
Yes.

Ranch, Daniel 1:03
And is particularly interested in providing education around perinatal supportive care and family centered care practices. And our second speaker is Doctor Cesar Garcia Canet. He's an assistant professor in the Department of Pediatrics and joined our team in August 2024.

Smith, Victor Philip 1:09
What?

Ranch, Daniel 1:20
He's an intensivist in our PICU, as well as A. Pediatric palliative care physician for our inpatient Pediatric and perinatal support care Services team, which is embedded within the Division of Pediatric Complex and Palliative Care. Doctor Garcia Knecht completed his undergrad degree at FSU in 2016, his residency at.

Smith, Victor Philip 1:20
OK.
OK.

Ranch, Daniel 1:39
Stream Health, Levine Children's Hospital, Mercer University School of Medicine in 2020, and then his Critical Care Medicine Fellowship at Holtz Children's Hospital at the University of Miami in 2023, where he also served as Chief Fellow. And finally, his Pediatric Hospice and Palliative Care Medicine Fellowship was completed at Saint Louis Children's Hospital in Wash U in 2024.

Smith, Victor Philip 1:50

OK.
Yes.

Ranch, Daniel 1:59
Doctor Garcia Kennett's academic interests include teaching communication skills to trainees ranging from the delivery of bad news, eliciting goals of care, and facilitating an effective multidisciplinary and multi-subspecialty family meeting. He HAS A. passion for narrative medicine research, which he hopes to continue to dive into. So once again, as A. reminder.
If you log on, please mute your devices. The CME code will be placed in the chat periodically, so please don't harass Delia or anyone else on the committee. And you guys have the floor. Thank you.

Smith, Victor Philip 2:31
Excellent. Thank you so much. So talking a little bit about information for today will be from a trauma and surgical lens, tools for palliative care and end of life management in adolescents and young adults.
Thank you for the introduction. We have no financial relationships to disclose. Some of the objectives for today will be understanding palliative care principles in adolescent and young adult population, utilizing advanced care planning tools, as well as being able to structure a family meeting and engage in goals of care conversations with patients.
As well as their families. Additionally, we'll be looking at the ability to recognize end of life signs and symptoms and have some of the basic skills to be able to manage this. So looking first at case one, so MP is a 19 year old female with a history of cystic fibrosis and moderate pulmonary disease who presented to the emergency department after.

Leigh Shapleigh 3:10
Yeah.

Smith, Victor Philip 3:22
Being struck by a moving vehicle while cycling, she was wearing a helmet and was thrown onto the pavement, landing on her right side. She complained of chest wall pain and mild shortness of breath, but symptoms worsened in route and required a

prompt trauma activation.

On arrival, she was tachypneic. Additionally, she denied any loss of consciousness, hemoptysis, or any kind of abdominal pain, but has difficulty speaking in full sentences.

Other information that will be relevant. She has a right pneumothorax with partial lung collapse. She went underwent emergent chest tube placement on day zero with resolution of that pneumothorax and was placed on 15 liters of high flow nasal cannula. It was able to be titrated down to 10 liters per minute. However, she's unable to tolerate further weaning.

Despite any kind of maximal airway clearance therapy, IV antibiotics and other aspects for supportive care, she otherwise has still remained on high flow and has been able to lean from there. So a little bit of a case just to kind of start off our discussion.

So when looking at adolescents and young adults, each year more than 11,000 adolescents and young adults ages 15 to 34 die of cancer and other life threatening conditions.

For a number of youth with chronic and life condemning life limiting conditions, those numbers are increasing as a whole. In order to get to facilitate the transition from curative treatments to end of life care, it's recommended the end of life discussions be routine.

Begin close to the time of diagnosis and continue throughout the course of illness. There can be some provider and parent discomfort surrounding end of life discussions with young adults. However, young adults have expressed a desire and ability to share their values, beliefs and preferences for the treatment.

End of life.

During normal adolescent development, individuals gain independence, formulate their self-identity, and strengthen both peer and romantic relationships that define their future role in life. Having a life-threatening illness challenges the the healthy adolescent development by compromising independence from parents or guardians. It interferes with school and social interactions and potentially can cause physical and emotional changes, arresting further development.

Additionally, allowing adolescents to be more involved in their healthcare decision-making process, especially at end of life, can be of great benefit to them in helping to reestablish their newly formed autonomy and their sense of purpose.

For the young adult patient, developmental tasks are complex, including issues with self-identity, evolving interdependence, intimacy, the redefinition of family roles, continued physical and cognitive growth. And then, as a result of all these, young adulthood is a time of great potential, yet also great instability.

This instability consequently leads to a particular set of burdens on young adults, especially whenever they're leaving living with a serious illness. Young adulthood really is this crossroads where a childhood disease transitions into more adult-like patterns while also trying to deal with the emotional aspects of entering into adulthood.

Young adults living with serious illness have to navigate this already complex time with the added burden of integrating their patient identity into that picture.

The young adult living with serious illness. They have developmental progression that's altered by their needed dependence on others for their medical care. This places them at high risk for inadequate development for future adult roles and the chance for their treatment overall to be compromised. Literature gives heavyweight to the impact that ongoing development has on caring.

for young adults and the discussion of how palliative care can be applied to adolescents. It must be in the context of the normal elements of development that we already see, as well as trying to take on this aspect of a serious illness.

And then the further this next few slides is going to talk a little bit about the impact of physical, cognitive, psychological, social and spiritual development and how those domains impact ongoing care for the young adult.

So here's just a few concepts that adolescents and young adults may cope with as they deal with integrating both their patient identity with their own development and growth. Just a few of these just to see if what they trying to cope with.

A little more specifically, first let's talk a little bit about their physical development. So young adults living with serious illness may have delay in physical or sexual development. Physical changes associated with the disease can demoralize young adults.

And this evolving self-identity is rooted often in the physical growth associated with becoming a mature adult.

Adolescents may be willing to accept a heavy symptom burden in order to maintain more of their independence and forego the sedating or debilitating side effects of certain treatments.

Frequent assessments of interventions and rapid titration are really key elements that help address those significant symptoms because young adults are known to experience a heavier symptom burden compared to other age groups.

Additionally, incorporating non-pharmacologic therapies of care such as physical and occupational therapy, meditation and other supplementary therapies can aid in the management of their symptoms as it provides a space of control for the adolescent.

Yes.

It's known in terms of cognitive development that brain development has been demonstrated to continue through the late 20s, and that as part of that, those increased connections between regions of the brain, myelination and other synaptic pruning has been seen on imaging of the young adult brain.

Overall, there's still evolving aspects even at that time for abstract thinking and executive function, so it leads to improved ability to evaluate risk reward, problem solving and regulation of emotions.

Early young adults who are living with a serious illness often struggle with the complexities and nuances associated with medical decision-making, and the presences of these illnesses can really affect their ability to evaluate a treatment process and also may inhibit their progression along the developmental spectrum.

Can even sometimes have regression in terms of their thinking process returning to a more childlike or concrete thinking pattern.

Reinforcement of autonomy is really important. It's achieved through a balanced approach. That's where the clinician is providing support, fostering independent thinking and offering assurance statements that the patient is not alone in her decision making.

Using more of a shared decision making model, the provider really can better manage the clinical uncertainty as well as help to make sure that there's not non adherence that can be commonly seen in young adult care.

For adolescents who are facing serious illness, the combination of isolation from their peers due to medical issues, as well as a lack of mastery of complex emotions and difficulty with coping really can all contribute towards mood or anxiety difficulties. So please keep in mind that depression and anxiety can easily go.

Diagnosed or overlooked and the difficulties associated with a patient trying to deal with the complexities of a serious illness.

Losses, especially related to physical changes, can be really difficult and and lead to difficulties with identity formation or self-image.

Also, anticipatory grief is something important to consider in patients with serious illnesses, because anticipatory grief is often proportional to the loss of each person's perceived life that's yet to be lived. Adolescents facing a complex illness may have many years not fully lived.

And future years lost due to early death.

This burden of anticipatory grief can be quite high, and it can be difficult for the patient to process and articulate this information. Other family members can also experience the same aspect for anticipatory grief, so the support structure of the adolescent can also be further impaired.

The impact of illness on psychological development can be really variable, or an adolescent could fall anywhere in the continuum of maturity beyond their years to more of a regression to a childlike thinking pattern.

Young adulthood is really a time of defining one's values through the experience of life goals and education, careers and relationships. So the social aspects for growth can really be stunted as well. There's an increased responsibility for finances, community and planning for the future.

Future and this social pressure can be felt not only by the adolescent, but also others around them who they feel interconnected to. If there's a significant other or a spouse for the young adult patient, and they try to take on that aspect for the social for them as well, especially trying to cope.

Awuku, Angela 12:36

But.

Smith, Victor Philip 12:40

It don't listen to the.

Face of the illness clinical experience really has demonstrated that young adults have to learn to practice these newly defined values outside of the traditional relationships of school and their workplace, because those might not be available to a young adult patient who's who's dealing with a serious illness.

Telling others about their illness can really be difficult for many patients, especially in work and new dating relationships. Partially, this is because peer responses can be variable and there's uncertainty in that response really can be threatening to the developing self-identity of the patient.

Who is considered of social importance to the young adult really can vary and change a lot over time. Who they found really important in their decision making may not be the same whenever they first had their initial diagnosis versus the ongoing questions and discussions around their.

Ongoing clinical care.

A patient support group can be shared by both friends and family, and sometimes equally. So while it may seem atypical, the support of a friend or a significant other may be just as impactful in the young adult's decision-making as that of their parents.

It's also important to consider some of the spiritual aspects as well. Even without the complexities of illness, many adolescents struggle with defining the personal, spiritual and religious beliefs and practices for themselves. Providers can facilitate ongoing conversations to help and assist in that spiritual development.

Or specifically in recognizing that that is a need and be able to hand off to the appropriate service or chaplaincy program. Consider providing assistance with finding these resources for young adult patients as they start to conceptualize what their spiritual identities are while having to face their own mortality.

Here's a little bit of a summary for some of the concepts that we just looked at that's available for you in case you wanted to look back at something into the future. Really, it's just a summary of what we had already discussed.

So talking a little bit about coping with medical decision making and the advanced care planning process. So young adults face certain unique psychosocial stressors at end of life. So there can be some specific psychosocial interventions that can be helpful. So reaching out for that psychosocial support from.

Our psychologists and other support and counselors can also be really important. While facing death at any age is extraordinarily difficult, there are some special challenges that should be acknowledged when young people face death as their independent life is just beginning.

Adolescents crave autonomy and should be given choices about their care whenever possible. Since honest and open communication is crucial, care conferences can often be a really helpful tool. And then trying to maintain and respect the young person's privacy is also paramount.

They should be given choices about such things as visitors and whom they want the information to be shared with.

They often agree that the loss of relationships that are just beginning to form and should be encouraged to maintain connections with peer groups whenever possible.

So this is just a little bit of another table just showing some of the different developmental issues and the demands of illness that really can end up having further impact on these developmental issues. It's difficult to form intimacy if there's isolation. The demands of illness may, you know, call for vulnerability in a space where the patient.

Wants to have in vulnerability, so just kind of some of these back and forth push and pull.

So when coping with medical decision-making, it's important to have positive physician communication with the patient and family. Honesty, respect, compassion and accessibility are all critical during this phase, regardless of whether it occurs in the pediatric or the adult setting.

It's often a challenge for providers to to gauge the appropriate level of the child parent involvement. Often it's seen for pediatricians to frequently err on the side of communicating more with the parent, and that's more out of habit, whereas the adult providers more run the opposite risk and.

Often end up communicating more so just with the patient leaving out the parents. As best you can, try to ask the patient when they are alone what their preferred level of involvement for their support people are and who those support people would be to to make sure that their their group that they have to surround them in their medical decision-making process is present during those discussions.

Talking a little bit more about advanced care planning. So advanced plan, advanced care planning documents and directives provide patients with the opportunity to express their preferences for how they want to be treated if they can't speak for themselves, allowing a young adult involvement in that advanced care planning process.

Can help both the parents and the patient alike make informed decisions, alleviate distress, avoid decisional regret, and improve the patient's quality of life because it's been reflective of their religious, cultural, and family values.

Terminal illness that presents with a young adult is often exceedingly difficult and contradictory, as we had covered in that previous slide. Things like dying, yet in their nature and developmental having a need and want to live. They're concerned about their lack of achievement.

Yet at the same time believe that they should be immortal and they wonder if they will be remembered.

The avoidance or lack of conversation about impending death by adults around them creates a sense of isolation, fear and anxiety. Patients are also often unclear about how to say goodbye or how to communicate how they wish to be remembered.

Often that then places the young adult at risk for dying in an emotional isolation.

So providing some kind of method for them to express their views and express what their beliefs and values are is really important. One of the ones that we're going to talk about is Voicing My Choices, which is a guide really to work through for the patient and with the help of the healthcare provider to be able to help define these values and goals.

Such conversations need to be tailored to the needs of the individual patient and the family. Having these conversations early on really paves the way to subsequent discussions that can then go much more smoothly. Don't ever feel like you have to have one of these conversations all at one time.

At later time points, the earlier held conversation can then be reviewed and then confirming with the patient if they still hold those same beliefs as they may change over time. And really good communication is the heart of that advanced plan, advanced care planning discussion and it really should be made a priority by all of those involved.

Helping to understand what the patient's concerns are really helps the provider better relate to the patient's treatment choices.

So when having an end of life discussion related to advanced care planning, the research has suggested 3 core components. So first it's understanding, then reflection, and then discussion. This model really emphasizes the importance of the patient's understanding of why advanced care planning is important.

The components of the process, as well as the advantages of planning and the consequences of not planning. A critical component is ensuring that patients understand their diagnosis, their treatment options, potential outcomes, and the chances of survival.

An essential element is the success of end of life discussions is identification of the patient's personal goals, values and beliefs. It often is A. question though of how do you know if A. patient is ready for that discussion or not. So there is an advanced care planning readiness assessment as A. way to be able to evaluate their comfort. And it's some of these yes, no questions here regarding the patient's opinion of whether talking about what would happen if treatments were no longer effective would be helpful to them or not, whether talking about medical care plans ahead of time would be upsetting or not.

And whether they would be comfortable writing down or discussing what would happen if treatments were no longer effective. This is A. way to be able to 1st bring up these concepts to even see if A. patient's ready for the discussion.

Provider can then encourage the patient to communicate with their chosen support system, their family members and their healthcare providers regarding these overall goals.

I'll now talk A. little bit more about voicing my choices. So with when discussing end of life with young adults, it's challenging not only because of the sensitive nature of the issue, but also because of the need for A. developmentally appropriate approach and language.

So this is an advanced care planning guide designed to assist young people living with serious illness and communicating their end of life preferences to their family, caregivers and friends.

So the initial page of Voicing My Choices provides kind of A. brief overview with the purpose of the document. Additionally, it offers comfort and purpose to those who have who may have mixed feelings about utilizing the guide.

It informs the young adult that document, uh, the document completion is based on their thoughts and desires, illustrates their autonomy, and then it's important to know that that they can fill out this document in its entirety or to whatever extent they feel most comfortable. They don't. They aren't required to either complete it in its entirety.

And they don't have to go through it in in the sequential order that's there. They have the opportunity to choose what they feel is most relevant.

They are encouraged to utilize the support of the available healthcare providers around them because A. lot of the concepts and terms can be difficult to understand or think about.

There's 9 sections and each section is A. separate module that's then tailored to the concerns. We're gonna kinda go through some of the specific pages in here, but just A. little bit of the information as you're going through it.

So here's what it looks like.

And then here's one of the examples of one of the page. So it talks about how I would want to be comforted, looking at I would feel comforted by and these lists of available options that can sometimes be A. prompt for A. jumping off point.

Additionally, it gives them the option to write in some of their other comments as well if they.

More specifically, want to label what they find important.

One of the other pages is then how I would like to be supported. So the ways I would like to be supported are by family and friends, visitors whenever possible. Please ask me before visiting. So some different options for them to choose from so they know what options are available.

And then whenever they're specifically talking about the my voice aspect, that's again more of kind of these written in options that are more specific.

Some of the more specific options around medical care would be looking at, you know, the ability to allow or refuse tests, medicine, surgeries, who they would want to act on their behalf in terms of arranging for. So trying if you're trying to arrange for hospital.

Or Hospice admission, admission to A. facility and then, you know, allowing somebody else to make decisions for them after their conversations that they've had about what's important to them.

It also prompts them to be able to help choose the person that they would want to help in this decision making process.

Here's A. little bit of A. sample conversation that could be used to help A. private A. provider identify A. surrogate decision maker. While we are hopeful that your treatment will be effective against your disease, we have learned from other families like your own.

That not suggesting that you give some thought to some difficult issues early on would be irresponsible of us. For example, it would be great if you would communicate with each other about who would be the person to make medical decisions for you if you became very ill and not able to do so on your own.

And then looking some more at, you know, these treatment and treatment decisions, if treatments are available that may cure or improve my disease or disorder, I would like life support treatments provided to me to help me survive or I would not like life support treatments to be provided.

And again, with these sort of discussions, it's really important to be able to be working through this guide with the patient, not necessarily just handing over this page and saying please work through it on your own.

Another example of how to discuss life support treatments. So although we are hoping that this next treatment will be helpful, many people your age have told /US that they found it helpful to have A. say about what they would want or not want if treatment doesn't go as expected.

Often people your age helped create A. guide to so that some of them can put down on paper the things that are important to them. Here's A. guide to be able to go through some of this information. Would you be interested in working through it together?

Additionally, you know, if you're trying to look for this guide, it's free to download. It can be found at the National Cancer Institute, but really the easiest way is to then be able to go through. If you look for that online, it's one of the first, you know, few to pop up.

And then just thinking about, you know, the importance of advanced care planning, participants have identified items pertaining to making medical decision treatment as the most stressful activity, perhaps indicating some uncertainty about how they want these types of decisions to be made. Health professionals may want worry that discussing end-of-life plans are presenting an.

End of life planning document may send A. message that the medical team wishes to withdraw care and that death is imminent or that will destroy hope. However, evidence HAS really shown that adolescents and parents really appreciate an open and honest discussion, and parents may feel resentful or feel fearful later if the topic HAS been avoided.

Additionally, these are often things that the adolescent is already aware of and already feeling, so being able to name that emotion and name that need is really important. Reviewing the advanced care planning document can provide an opportunity to address misconceptions and unrealistic expectations before major medical events occur.

And it also ensures that they have the best interests and wishes of the patient are being met. Knowing what the young adult wants can be A. great relief to parents, and communicating one's concerns and wishes can be A. great relief to the patient.

And now I'm gonna hand over to Cesar to be able to go through, uh, some of the further slides.

CG **Cesar Garcia-Canet** 28:16

Thank you so much Victor. If you could hit the next slide for me when I when I give you the heads up.

So case #2. So GM is a 16 year old male status post an MDC where he was an unrestrained passenger. He comes to the PICU following initial assessment and management in the true.

He sustains multiple facial and cranial fractures and will require extensive maxillofacial reconstruction. There's concern for widening between the C1 and condyle along with AO instability.

Undergo spinal fusion, has critical polytrauma and has suffered a severe traumatic brain injury. So given extent of injuries and prognosis, a family meeting is held. Next slide.

So the the American College of Surgeons, along with the Trauma Quality Improvement Program, has a lot of palliative care best practice guidelines and really. Even though it's specific or it can be specific towards trauma, you can really apply it to general Pediatrics and or your particular subspecialty. Next slide.

So it says that best best practice palliative care is delivered in parallel with life sustaining care through the continuum from injury through recovery. The unit of care is the patient and their family, mom, dad.

Siblings core palliative care can and should be provided by teams, so you can substitute trauma for primary care teams, subspecialty teams that are taking care of the child, even if palliative care.

Is not available in your area. Optical palliative care is interdisciplinary, so you have your physicians, your nurses.

And your psychosocial and rehabilitation providers and optimal care requires you as the physician and nurses to have basic competencies in primary palliative care, pain and symptom management and end-of-life care.

Next slide.

So a couple of considerations when dealing with children with TBI. While the Glasgow Como Scale is an accurate predictor of death, it's less useful in predicting functional cognitive.

Outcomes in in survivors. This is one of the reasons why, as best as we can give estimates of prognosis, we tend to not be so great at it.

And you also have to focus on conversations of potential cognitive and functional outcomes to determine their compatibility with goals of care and advanced directives.

Next Next slide.

Specifically for peds, decision making for older kids and adolescents should include the patient and their assent if possible, and then age of consent for medical treatment varies by state.

And you do want to give bereavement care for the family, especially not only for the parents but for the siblings, although this poses a unique challenge, especially in resource limited areas.

Next slide. So just as an aside, in Texas, a minor can generally consent to their own medical, dental, psychological and surgical treatment if they are active duty within the US Armed Forces or if they are 16.

Years of older and reside separately from their parents and caregivers and manage their own financial affairs. And minors can consent to certain treatments without parental consent in certain specific situations, and these include.

The diagnosis and treatment of sexually transmitted infections and communicable diseases. Services that are related to pregnancy and mental health counseling. Next slide.

So we're going to talk a little bit about the family meeting and how to approach it. And really prep preparation is key. So a family meeting can also be called the family conference or a care conference.

Since we're in football season, we'll use a game time analogy here. The overarching theme for these family meetings is that we cannot take away how these family discussions may make the family feel, but we can ensure.

That the family feels heard, that the information presented has been understood, and that they feel cared for and respected by us. Next slide.

So our goal or other goals in the meeting are to empower and support the family during these difficult times, offer an opportunity to share and clarify goals of care and other information. And it's really a safe environment where parents are also able to raise their.

Questions and concerns, and if it's going to be a very extensive discussion regarding the status of the child, really all of the healthcare providers that are involved in the child's care should meet before the family meeting.

And another thing to consider as well is that, you know, emotions may be high during the meeting and we'll talk about some of some tech, some techniques to manage those emotions both in yourself and in.

The family. And I always say that, you know, at the end of the day, it's the family that may or may not take their child home and deal with whatever medical complications. That child has and we just have the honor and privilege of taking care of that child either in the clinic or while they are inpatient. But really it's the day-to-day life that this family will be dealing with. Next slide.

So in terms of the so-called pre-game or tailgate before the family meeting, this is a good time to read over any medical and or psychosocial information pertinent to the child.

Are there any cultural, religious backgrounds that you have to be aware of? Who's going to inform the family of the potential meeting? Who will convene and organize the meeting?

And really, it's important to give a family the heads up about the family meeting to mitigate any unnecessary stress that may come about from not giving them the heads up or not giving them enough time.

This will also allow them to jot down any concerns that they may like to raise. They can seek additional support so that they feel that their voice will be heard. They can also ask who else would want to be there.

In order to support them. And you know, I always like to encourage our families to jot down any questions that they have before the meeting.

And our Pediatric and perinatal supportive care team has a ton of notebooks that we have available to give to families for that reason. But it can also be, you know, you you can provide them a piece of paper and they can jot down.

Any questions that they may have again because in the moment you may they may just blank, but if they have a structure that they want to follow beforehand, it goes a long way and makes the meeting run smoother.

You know, here in Texas, particularly in South Texas, we have a very large Spanish speaking patient population in addition to other languages as well. So it's very, very important that even if you speak the native language of the patient to have a certified medical interpreter.

In the in the meeting, ideally in person but video or phone if not and again the provider only meeting beforehand is is very important during this pre-game.

Time and it will include all the subspecialty teams and the ancillary support staff.

Next slide.

So now we're in the family meeting. So we're in the actual game we're in, um, we're in uh, kickoff. And here you really wanna see first and foremost when you start off the meeting and you do your and you do your interactions, what is the?

Family's actual understanding of the child's current condition, and this is a good time for the parent to give us summary with the cat with the caveat that the child may or may not be in this meeting depending on their level of ascent.

And or their ability based off of neurological status to be present in the meeting.

Then you as a provider want to update the child's current condition and current prognosis.

With a medical summary that is easily understandable by the family. Allow them to ask questions, allow time for pauses and recognizing emotions. Avoid medical jargon and address any fears that the family may have as a as appropriate.

So once you see what their understanding is and you clarify things and you provide an update, then you can explore the child and family's goals and wishes. And it's very important to note that this is in flux.

The wishes that they may have now might change later overtime based off of the child's biomedical status, and that's OK. Um.

And a good way to, you know, form this question is, you know, tell tell me about your child outside of their disease state. How? How do you want your child?

To be taken care of. Those are some good conversation starting points. Then finally you want to discuss the options that are available.

There should be pretty clear documentation about the meeting. You know, a lot of the times our social workers go to the meetings and they do this, but the primary team can also do this as well.

Or the subspecialty team who who attended the meeting? What's their relationship? What were the issues discussed? What were the outcomes of said discussions? Who's responsible for following up? And are there any plans for future meetings to talk about any issues that were unresolved?

Salt.

So a good mnemonic for giving information, either good or bad, is the spikes mnemonic. So S stands for setting up and starting.

So you you mentally rehearse and what you're going to say and you and you also say the reason why we're having the meeting. P is for perception, so you elicit the patient.

Or the parents or the family's perspective of what's going on, then I is in then I's invitation. And this is important because you want to give permission to say, is it OK if we talk about?

What's going on and what the potential next steps are. If they say no, it's fine. It could be that they're just not ready. And then at that point, you know that you can talk about it at a later time unless it is a decision.

That needs to be made right then and there. And in that case, a good strategy can be, you know, I know that this is very distressing for you as your provider. I want to make sure that the care that I provide.

Is the best for your child, and I really feel that it's important that at this time we talk about this because the parents might not know that there's a certain urgency to set discussions.

So once they give permission, then you share your knowledge of what's going on and that's KE is being in tune to the emotions of the family and then S is strategy and summary. Next slide.

Another strategy is the ask, tell, ask strategy. So you know you ask them what you think, what they think is going on, then you tell them what is going on.

And then you ask them again, is there any questions? And there's various iterations of this mnemonic. There's ask, ask, ask, ask, tell, ask. There's ask, tell, ask, ask, ask, ask.

All to the point that you know you let them lead the conversation with what they know, because it's OK if they have a limited understanding of what's going on to to continue to ask them.

Until they have clarity and then you go into the tell. Next slide.

And then the nurse mnemonic is a good mnemonic for to use when dealing when when responding to emotions. So N is name the emotion. So it sounds like this has been frustrating.

You is understand the emotion. It must be so hard to be in pain like this. Our is respect the patient. I'm so impressed that you've been able to keep up with this treatment, or I'm so impressed that you're still here and you're still present for your child despite everything.

That may be going out outside of the hospital as a support. My team will be here to help you and your family regardless of the decision that you made and E is explore this emotion. Tell tell me more about why you feel this way and not only is this good for family meetings but.

In everyday practice as well, especially when we may be dealing with a quote UN quote difficult parent because emotions are running high.

So back to case number #2, the parents decide for a tracheostomy and G tube placement. His his hospitalization continues. Unfortunately, he needs numerous EV DS, ICP monitors, a lumbar drain.

To manage elevated I CPS one has once his EB DS have malfunctioned and he experienced this as the sequelae of severe TBI such as diabetes insipidus neural storming.

And his family cannot bear watching him suffer so many complications and want to speak with you regarding how they see his current and future quality of life. And again, this goes back to these goals of care flux and they change over time based off of the biomedical status of the child. And that's OK.

So another family meeting is had, family chooses a comfort oriented pathway and his coach has is changed to DNR comfort and a lumbar drain is removed and end of life management begins. Next slide.

So this study by Tobridge at all showed us what some of the modes of death within a Children's Hospital are, where they take place most likely, and there are reasons why. Next slide.

So it was a retrospective chart review of all of the patients who died in a Children's Hospital between July 2011 and 2014 of June, and it involved the demographic and diagnostic information, hospital length of stay, location of death.

Whether a palliative care consultation was was provided, and in the end there was 5 mutually exclusive modes of death that were assigned to each patient. The vast majority of the deaths were from heart conditions or congenital genetic defects.

As well as being preemies or and followed by neurological and neuromuscular conditions and rest and respiratory and the vast majority as you can see and there's these are these.

A&B show exactly the same thing is that the vast majority of deaths took place in an ICU and and it differentiated between whether it was withdrawal of technology.

Or if the family chose not to escalate care, and those were the two main ones.

Followed by a code.

Next slide.

So how to initiate an end of life conversation is quite challenging, but you want to focus on where would the family like this to take place? Do they want to be in the hospital? Do they want to be at home? And it's very important to discuss the.

Timing of death, especially the uncertainty around this. As providers, we're good at a lot of things. Unfortunately, prognostication is not one of them, but we do try our best.

Which is why it's important to always say the possibility of the child living longer than expected and what this may entail. And it's also important to alleviate as much distress as possible in terms of what to expect by discussing what the symptoms might be at end of life. Next slide.

The study by Brodin at all in 2023 showed that the preparation of symptoms and access to resources may help ease parental perception of end of life suffering, and this study by Zal Schuler in 2016.

Showed that most parents of children with severe neurological impairment wish to actively share in end of life decision making. End of life. Next slide.

So in terms of end of life signs and symptoms, particularly towards the end, some of the signs and symptoms to look for around a week before they pass are peripheral edema, cool extremities.

Decreased speech dysphasia to solids and overall just impaired cognition. Next slide about two to three days before death. You'll see the Chen Stokes rest respirations, kind of like the seesaw type of respirations with periods of apnea.

Brief periods of apnea, decreased response to visual and verbal stimulation, cyanosis, neck hyperextension, pupils may be non-reactive and then two days or less before you'll see these more prolonged periods of apnea.

Hunting on expiration because of obstruction from their vocal cords. You'll also hear the death rattle as well, which is just gurgling from pooled secretions due to loss of inability to swallow secretions.

Respirations with an open jaw and then a pulseless radial artery is normally a very good predictor that death is imminent in terms of nutrition at the in the last few days.

It's typically no longer needed for energy, for growth and energy. There's also a decreased desire to eat, and forcing food can bring discomfort, such as Constipation, nausea, vomiting, et cetera. You can trial.

A pleasure feeds or a trial of feeds if the patient desires or as they tolerate it. But as soon as you start to notice discomfort, abdominal distension, bloating, diarrhea, et cetera, that's a good time to stop.

It's important to communicate to the parents that they're not starving their loved ones, that this is that not eating is a natural part of the dying process. In terms of hydration, receiving fluids tend to cause discomfort and this is really because.

At the eminent end of life in the last few days, these fluids no longer are being used by the body and they collect in the extra spaces of the tissues and organs and lead to.

Fluid overload and swelling and pulmonary edema. Um.

You can encourage the family to keep the child's mouth moist with mouth swabs, even small sips of water or or crushed ice if they have the cognition at that time to do so. Next slide.

As we talked about, you'll see cool extremities modeling. The patient can also have a fever as well, or they may be hypothermic. There there'll be a lot of fluctuations in body core temperature.

Next slide. Um.

Patients may see, reach out or talk to deceased persons or spiritual figures. They may have other hallucinations unless they are extreme and combative, in which case you would use medication for it. These are typically.

Not not distressing enough to give medications.

Um.

OK, so for the progressive restlessness, restlessness and confusion that is seen in the very end of life, you want to think of why. And a good reason is is just to assess. Is it because of lack of oxygen? Is it because of rising levels of unnecessary?

Substances in the blood because the body's not metabolizing anymore. Is it pain? Is it anxiety? Is it delirium? And this is a good time to administer medication. So if you think it's due to pain, you really want to start with opiate boluses and then escalate if needed and kind of.

Like this stepwise approach, you know it's been, unless it's been a terminal extubation where you think that the patient might live a bit and they've already been on drips, then you would just continue those infusions and just escalate as.

Needed on your drips based off of the symptoms that you see for dips for if you could go back to the previous slide for me. Thank you for dyspnea.

The above help as well, as well as benzos and oxygen administration, but really it's the opiates that are the staple. And just as a refresher, dyspnea is a subjective sense, the subjective sensation of difficulty breathing.

For anxiety you give benzos, and for delirium you can give, for example, Haldol.

Avoid benzos if possible because it worsens delirium. Next slide.

Oxygen can be a comfort. Just be mindful of the tubing that you use because it can irritate the family and increase their. It can irritate the child and increases or her anxiety. You want to position a fan in.

Front of the child, because that also helps with that feeling of air hunger reposition every few hours or so. Next slide.

And really, opiates work by blunting the perceptual sensitivity to the sensation of breathlessness because they depress the respiratory drive and then this sends decrease.

Charges to the perceptual areas in the cerebral cortex and less discharges means less awareness of respiratory effort. Next slide.

In terms of the death rattle, again, this is due to the pooling of secretions because the patient can no longer swallow. There's type one and type 2. Type 1 comes from the upper airway, comes to type 2 comes from the lower airway and.

You can treat it via gentle suctioning. Avoid deep deep suctioning, especially if they have a tracheostomy. Turn the patient from side to side, elevate the head of the bed and then it's a good time as well to use your anti muscarinic.

Agents, and while they don't necessarily dry up the secretions, they will prevent new formation of secretions. Some good ones to use would be hycosamine drops or glycoperylate. I tend to avoid.

Atropine drops or scopolamine patch because they can cross the blood, blood brain barrier and make delirium worse. Next slide vital signs at end of life. So they're really no longer telling us much information at this point, particularly at.

The at the at the end, so we check them less frequently, if at all. Blood pressure may be lower, you may be bradycardic, you may be tachycardic.

SAT probes are not really accurate because of decreased blood flow to your extremities. Pulses though are weak, especially your your radial pulse, and this is really a good.

Marker next slide.

So just to wrap it up, you know, much like what Doctor Smith talked about, kids tend to ponder what their lives meant, whom they've touched, and what they have accomplished.

When the dying can't talk, they can still hear, even up to the last moment of life. The sense of hearing is the last sense to go, so always encourage your parents.

To talk to their child because they can hear and have the parents use reassuring words and then be mindful. Next slide and then just be mindful of what's called the energy surge. It could.

A short period of improvement up to a day or two before passing, where the child may be talkative or have increased strength. This rally is natural but comes before the body begins to actively shut down. Next slide.

So just some final thoughts.

Next slide.

Each patient dies at in their own time, and it's not uncommon for sometimes the patients to die when their parents leave the room. They may require higher doses of meds at the end of life than what they've needed in the past.

especially if they've been opiate tolerant. Next slide.

It's important to reassure the family that is the disease process itself and not the medications that we are using that is hastening death, especially with with judicial

use of our end of life medications.
Next slide.
And that concludes our presentation. We have, we're about 30 seconds over, but we'd be happy to take any questions if you have any.


Ranch, Daniel 1:00:35
Thank you very much for that wonderful presentation, Doctor Smith, Doctor Garcia-Canet. As you said, we're out of time, but so people need to log off. That's OK. There are a couple of questions in the chat. First one's from Doctor Gross. He asks. I've been in conferences when pages went off with people coming and going during serious discussions. How do you handle this?

CG **Cesar Garcia-Canet** 1:00:57
So you know, I have, I I I have had that happen before. A good strategy would be to designate one team member to.
Hold the phone or hold the pager and not be present during the meeting. This may be a resident that is not taking care of the patient.
It can be a nurse or any of the advanced practice providers that may not be following the the patient, just so that the sole focus is.


Smith, Victor Philip 1:01:35
The.
OK.

CG **Cesar Garcia-Canet** 1:01:45
For the patient and their family.


Ranch, Daniel 1:01:52
Great, thank you. And second question is from Doctor Asanasan. In the 1st and 2nd cases, the strategies described seem to assume that the provider slash team had developed significant relationship with the patient and family. In the post trauma scenario, there is generally limited time to develop these relationships.
Are there any suggestions that you may have to address these conversations in these and other similar situations?

Smith, Victor Philip 1:02:15

Sure. I can talk a little bit about that. So I I think first just trying to um have multiple conversations over time I think is really important in that discussion because that does allow that um uh overall.

Rapport building and getting to know the family and also knowing that if there's an opportunity to, you know, help to build towards the conversations, if it's something that, you know, sometimes in trauma scenarios the decision has to be made right then, but if at all possible, trying to give time to help us.

Establish that understanding of the patient's and family's values.

Ranch, Daniel 1:03:00

Thank you. I don't see any other questions in the chat. Anyone else have questions? Whoever might still be on.

If not, thank you everybody for attending Grand Rounds. Thank you again, Doctor Smith and Doctor Garcia-Canet, and everyone have a great day.

Cesar Garcia-Canet 1:03:17

Thank you.

Smith, Victor Philip 1:03:17

Thank you.

◉ **Calderon, Delia** stopped transcription