How to Build a Single Ventricle Program - Pediatric Grand Rounds-6-13-2025-Meeting Recording

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52m 24s

Kamat, Deepak M started transcription

Kamat, Deepak M 0:43

Good morning.
It's 7:30 and it's time to start our grand round. So welcome to pediatric grand round.
Just a reminder that this is the last grand round for the academic year 202425 and we'll start again on July 18th.
That will be the first grand round.
For the next academic year.
So Doctor Columba, thank you for joining us today. Doctor Abarbanell will be introducing this morning's grand Round speaker, doctor Abarbanell.

Abarbanell, Ginnie L 1:12

It is my pleasure to introduce Jamie Colombo.
She's a good friend. Excellent clinician and outstanding human.
She did her training at University of Arizona in Tucson and her fellowship at UVA.
She's a pediatric cardiologist at Vanderbilt and leads the single ventricle program at Vanderbilt. I got to know Jamie when we work together in St.
Louis at Washington University. So I'm excited for her talk.
I'm sure it's going to be amazing and with that.
It's up to you, Jamie.
Me.

CN

Colombo, Jamie N 1:42

All right.
Sounds good.
Thank you so much, Janine.
Thank you for having me today.
I'm excited to be with you all today.
We're going to talk about how to build a single ventricle program.

I have no disclosures.
By the end of this presentation, I would like the audience to be able to describe why the inner stage period is deemed so high risk.
I'd like you to be able to formulate ideas about creating your own single ventricle program or other boutique program, and be comfortable with assembling a team of providers for a multidisciplinary approach.
Today, we're going to talk about The Who, what, where, when, why, and how to build your own program.
1st we have to start out with the Y.
Talking about hypoplastic left heart syndrome, this is quite rare.
It occurs in about one in four 300 infants born in the United States before the 1980s.
It was almost universally fatal by one month of age.
Today we perform a three stage palliative approach that has improved survival, but that's only to about 65% at six years. Mortality between stage 1 palliation and stage two. What we collectively call the Interstate period remains high.
Up to 20% in this population.
So let's talk a little bit about risk mitigation.
How can we make this better?
1st, as a fetal cardiologist, I have to think about prenatal detection and primary obstetric education.
Over the last decade, the standard obstetrical approach initially started with what is just a four chamber view of the heart posterior.
Here we see the spine anterior.
This is right.
And this is left.
And this was the initial start of what obstetricians would look at.
Simply looking at 1234 chambers of the heart and saying that the heart was structurally normal today with expansion of obstructed care and education, we now also look for what we call a three vessel view.
This again looks at anterior and posterior spine, back right and left. Looking at the pulmonary artery on the left, the aorta in the center, and the SVC are superior. Vena Cava on the right.
This is our Goldilocks slightly bigger of the PA.
Center.
Is in the middle size and your SVC should be considered your smallest vessel.

Sweeping up slightly higher, we can see where the pulmonary artery and the aorta connect.
This is going to farm our aortic arch later, adding color to this what we're looking for is to have the same color flow or colored picture in the same direction. If we see opposite colors, IE we see a red flow and a blue flow.
That should alert the obstetrician that there is a concern for.
An abnormal.
Heart defect.
In this view, this is a real live video of a patient with hypoplastic left heart.
Here again, the spine is posterior.
This is anterior.
This is right and this is left.
And here you can really only see 3 chambers of this heart.
This is the right atrium, the right ventricle and the left atrium back here, this little nub.
Oh, my video is starting to fail.
Is the left ventricle. This is significant for hypoplastic left heart syndrome and would be identified in a basic 4 chamber.
Review.
Well, why does this matter?
In a systematic review back in 2016, the folks at Toronto looked at whether or not this improved operative mortality. They looked at six different studies that were performed, and while they didn't see a change in postoperative mortality following the Norwood procedure, they did see a decreased rate.
Of perioperative acidosis, a decrease in preoperative risk for need for vasoactive support, they saw a trending risk for preoperative shock decreasing.
And they did see that patients who were screened prenatally had a decreased risk for ventricular dysfunction and a greater degree of tricuspid valve regurgitation, all of which are known to be poor prognostic indicators for patients who undergo single ventricle palliation.
Going back to our chart for risk mitigation, we have to think about what happens at the time that the baby is delivered.
We are looking for a baby to be delivered at term 39 weeks or greater.
We want them to be delivered at a large center where.
Can have immediate intervention and resuscitation. We want to minimize

preoperative risk taking them to a timely surgery and have technically satisfactory surgeries.
As a quick review, there are three stages of palliation for a patient with hypoplastic left heart syndrome. The Norwood typically performed within the first week of age is the most complex and carries about a 10 to 20% risk of mortality alone.
Here we use the pulmonary artery that is well formed and we create.
A new aortic arch, also patching the aorta to get rid of the coartation. We give them a new source of pulmonary blood flow.
Here is depicted a Blalock Taussig shunt.
And in this picture you can see what we call an RV to PA Conduit, also known as a Sano shunt.
We perform an atrial septectomy and we ligate the PDA.
Stage two is considered the Glenn procedure and this is typically performed within three to six months of age.
Here we get rid of the pesky shunt and we connect the superior vena cava directly to the pulmonary arteries.
This surgery carries a significantly less chance of morbidity, with less than 5%.
The same is true of the Fontan procedure, which is performed at three to five years of age, or we complete the circuit and we connect the inferior vena cava via a conduit directly to the pulmonary arteries, virtually separating the vast majority of the oxygenated from deoxygenated blood.
In the Norwood procedure, there are several risk factors that make you at high risk for undergoing this procedure.
This includes your gestational age, so those at less than 37 weeks are considered higher risk. A birth weight of less than 2.5 kilos, an associated genetic abnormality, a restrictive atrial septum being put on preoperative ECMO.
Also, infants who have poor ventricular function.
Are a significant amount of AV valve regurgitation are put into a separate higher risk category?
Interstage morbidity and mortality is also a big problem for this population.
Intersege again is between the first and second stage surgeries and we monitor them very closely for residual anatomic defects, which accounts for up to 75% of complications during the interstage period.
This can include things like arch obstruction or shunt obstruction, the development of new anatomic complications is also a problem.

Again, AV valve regurgitation.
Or piventricular function.
Volume load leads to a dilated heart which can lead to a poor squeeze. Inability to orally feed poor weight gain and illness, which causes impaired gas exchange, hypoxemia and dehydration all can lead to low cardiac output.
With the introduction of interstage home monitoring by the Children's Hospital of Wisconsin in 2003, patients were discharged with a home scale and a pulse oximeter. This allowed for better patient education and improved overall outcomes.
What is interstage home monitoring?
Well, patients are discharged with a home pulse oximeter and a scale to assess daily oxygen levels and weight.
Enteral intake is often reported and lumped, and regular phone calls are made to the family from the medical team to assess for any concerns. This may include a special team of cardiologists or surgeons or intensivists to be on the outpatient side to care for these patients and pat.
Are evaluated frequently, typically every one to two weeks.
Patients are given extensive education about what we call red flag concerns.
These are things like low oxygen levels, acute weight loss, inability to gain weight regularly, or signs of dehydration with less than 100 M LS per kilo per day taken in.
This is a graph from the Children's Hospital of Philadelphia that looked at a 30 year experience of the inner stage period and the outcomes for Norwood survivors.
What we can see is there is an overall decrease in mortality to about 10% during this 30 years. The first dip with Norwood survivors as depicted in the blue is with the introduction of the right ventricular to pulmonary artery conduit or the Sano shunt making for a.
More stable Physiology.
The second dip that we see is that with the introduction of the interstage home monitoring of interstage mortality which is depicted in red.
So what do we need?
When we think about program strategy and development, we must first think about who is our target population and who are going to be our team players.
What resources will we need to build our program?
Will we need nursing radiology support?
Feeding support, clinical coverage, social work, psychology, intensiveness care.
What are the goals of our program?

What is the purpose?
What are the financial objectives that we'll be looking for?
What services will be offered and what innovative offerings should we should our program have in order to support growth?
What must be done before we start analyze and optimize program capacity, determine recruitment and needs for growth?
An easy, multi pronged access points to create marketing plans, insurance provider outreach, community provider outreach.
And establish and monitor executive metrics.
When will we start? Both.
When we start the program three months or a year and when will the child be enrolled in your program?
Where will we play?
Well, where do the patients live?
What is their preferred location for services?
Do they prefer to be at the main site or an off site location?
Is your program considered a spoke or a hub?
And what services will need to be at main campus versus those that are dominant outreach?
How can we configure an advantage?
How should we take into account a financial impact?
What distinctive capabilities can you leverage for an advantage?
What are your programs, main medical collaborations and how can we achieve synergy?
And lastly, what will we consider a win?
Is it a quality project?
Is it safety?
Is it patient access to care?
A comprehensive patient care approach is it multidisciplinary or one provider?
What referral patterns will we be looking for and relying on and who might you partner with to gain the market share?
When I broke down our single ventricle program at Vanderbilt.
When I joined several years ago, I created a SWOT analysis looking at our strengths, our weaknesses, opportunities and threats. I knew that Vanderbilt was a large center with a large referral basis.

Had a dedicated nurse practitioner, but we had a lot of patient practice variabilities both on the inpatient and the outpatient side. Our ability and mortality rates could use some improvements, and I knew that there was opportunity to expand our care, streamlining a comprehensive care approach, establishing clinical GUID.
For our institution looking at advertising telemedicine approach, we also during the pandemic had had a drop off in our national pediatric.
Cardiology Quality improvement collaborative.
Patient enrollment.
I wanted to focus on decreased hospital length of stay, but I knew that threats would also be concerning.
Where are we going to get funding?
Where are we going to have the space to provide this?
Would I get provider by it and patient by in as many of our patients live far away?
Who would we focus on?
Well, our target population, I was looking at any patient with single ventricle congenital heart disease less than one year of age.
Patients who were shunt or stent dependent for pulmonary or systemic blood flow.
Cyanotic patients who required staged surgical or catheter approached and anyone deemed high risk by the Heart Institute.
A multidisciplinary team report results in multiple things, as dedicated by the literature. It improves patient centered care.
Enhances medical decision making.
Decreases emergency room visits and can decrease hospital admission and mortality.
However, there really aren't.
Any research guidelines for patients with single ventricle congenital heart disease?
So what are we going to do?
How can I support a team and how can I convince my division head that this is a worthwhile endeavor? What is our purpose?
I started with a mission statement.
To provide excellent continuous care for all patients and families with single ventricle or high risk forms of congenital heart disease through multidisciplinary collaboration and one-on-one provider support, thereby decreasing morbidity and mortality and mouthful. But it included all that I wanted to do.
The first thing I did is went to the literature again. The National pediatric quality, the National Pediatric Cardiology Quality Improvement Collaborative. Again a mouthful

NPC QIC is a large national international program that started with 43 centers and is now well over 70 centres around the world they.
Now have over 40,000 patients, 4000 patients and started in 2008.
Their initial goals were to decrease inner stage mortality.
Starting with a 40% mortality rate and decreasing that to 5.3% using a collaborative approach and research to improve patient care.
From here, they also focused on reducing growth failure during the inner stage period and reducing hospital readmission rate.
One of their first publications, way back in 2011, looked at the variation of outpatient inner stage care. When I thought about how I would get provider buy in for both.
Inpatient and outpatient side.
I knew that our patients while in the inpatient world were meeting up to 8 providers at a time.
A fetal provider, a NICU provider, a cardiology consult.
Cardiac surgeon an intensivist.
Probably another cardiology consult because they were there for so long and finally their primary cardiologist.
That may be different from all of the above players.
What this article showed me was that evidence suggests that when possible, management standardization improves inter stage outcomes.
This article described looking at three separate things, a medication list, a nutrition, a nutrition plan, and a red flag checklist.
And looking at communication between the outpatient cardiologist and the primary care physician, they looked at 100 patients enrolled in QIC. Looking at these clinical variables and looked at communication defined it as complete or incomplete.
It was complete. If the pediatrician received all of these three points.
And the same is true for the outpatient cardiologist. What they found was that only 45% of the outpatient cardiologists received information about patient medications, nutrition plans and red flag checks list, and only 26 of primary care physicians.
Well, where did the practice variation start?
It started with just simple discharge summaries.
There was a variation.
Who wrote the discharge summaries?
There was variation in how the patients were being fed. Were they being fed by mouth, by Ng or NJ2 by a gastrostomy tube? And even in the amount of caloric

density that these patients received?
Additionally, there was differences in the way that the patients were monitored at home.
Was it daily?
Was it twice a day?
Was it weekly?
Was it by home health or did it not specify?
This article made me ask more questions.
How can I decrease practice variation in our institution?
Can we make sure that the pediatrician and the primary cardiologist receive regular updates?
We can't change the surgery performed, but we can.
Place the patients into risk categories based on how the surgery went and their hospital course.
I can work with the ICU closely to streamline postoperative care and improve discharge practices. Once the patients are on the floor.
This is an example of a way that we risk mitigate our patients with hypoplastic left heart syndrome in the interstage period before they're ready to go home.
This is a risk validation score called the Neonate score. Looking at Norwood Type ECMO opioids at discharge, the presence of digoxin in their medical list.
Arch, obstruction, tricuspid regurgitation, and oxygen saturation.
With this, a score of 17 or higher suggests a high risk for interstage mortality.
They have up to a 3% risk of inner stage morbidity and mortality.
Tricuspid valve regurgitation, compounded by oxygen use. At the time of discharge, was found to be the highest risk factor.
With this, we said that we simply would not send our patients home on oxygen as one of our risk mitigators.
A score of less than 17% suggests a low inner stage mortality and a good course during the inner stage period. This is included in all of our discharge summaries when the patients are ready to go home.
Next, when when would we start this program?
Again, I went to the literature looking at nationwide, which is one of the few centers in the country that performs a hybrid procedure for their stage 1 instead of the typical Norwood procedure.
Still, high risk, but different.

They looked at patients starting at the beginning stages of fetal all the way through the stage two procedure.
In 2013, when they created their single ventricle program.
He created a multidisciplinary provider approach and knew, and I knew that we needed to expand upon this.
This is an example of what it looks like to become a member of our single ventureable team and be followed by our program.
We initially meet the patients in fetal life.
We follow them during the fetal course, communicating with the ob's and the surgeons, often having a surgical date in place before the child is even born.
We meet them again at the time of initial admission, discussing with them what might happen over the next several weeks.
We follow them closely during the interstage period, both in the ICU and on the floor. We focus on discharge when they are ready for that, and then we follow them through the outpatient side.
We again see them when they get pre admitted for their stage 2 Glen procedure and help with discharge coordination at that time.
We continue to follow them through their tube wean and often until they're 8 to 12 months of age.
So Tennessee is a large state. I knew that the where would be a complicated question. When we look at a map of Tennessee, it's very long and our patients come from a wide range about 65 to 75 of our percent of our patients do not live.
Locally in Tennessee, I knew that we would need social work support to help get them back to Nashville. In the diagram that you're looking at, the Purple Star in the center is Nashville.
This is where our main Children's Hospital is located.
The yellow stars represent our outreach cardiologists that refer to us from outside centers.
The green stars are just some of the dots from where our patients come from.
So how how are we actually going to make this happen?
Again, I went back to risk mitigation.
We had talked about prenatal diagnosis.
We had talked about what makes you high risk at the time that you're born, but I knew we needed to focus on family centered care to get our patients to buy in.
I created a list of goals for the first year.

Most importantly, first I had to identify a team.
To become involved with a multidisciplinary clinic, I met with everyone, I presented my ideas to cardiology to the fetal folks, to our general cardiologist.
To the floor, to the ICU. I walked the floors of the inpatient units meeting the therapist, the social workers, the palliative care teams, and anybody that would talk to me.
Then I presented their leadership team many times over those first six months until I could create a team of providers who is willing to care for this high risk population.
I'm really pleased to say that we now have a team of over 12 people involved in our single ventricle care.
I have two wonderful nurse practitioners who focus on inpatient and outpatient medicine. Following these patients through their course. I have two amazing psychologists who focus both on development as well as family dynamics 2 social workers who couldn't possibly be more dedicated, a speech therapist, an occupational therapist, a.
Physical therapist and a wonderful nutritionist to help our patients.
Scheme with.
Next, I knew we had to improve our enrollment in NPC QRC, increasing our patient volume, and I wanted to meet the patients early so that they were familiar with our phase and develop trust with our team early on.
In general, fetal patients will follow up every four weeks with a fetal provider. The first few visits are very overwhelming. Hearing all about what hypoplastic left heart syndrome is and what the course of the child's life will become.
I knew if.

JF **Jane Fried** 23:53
Here it is, Jenny.

CN **Colombo, Jamie N** 23:55
I knew if we could meet them during the third or fourth visit, we could begin to establish continuity with these families even before the patient was born. We could enroll them in NPC QIC.
We could hand them resource folders and talk about the importance of development and what that would mean for their course of their life.
Next, we moved on to continuity and communication and improving, improving

building billing, which is of course what my division director was most interested in.
I know these slides are small and it's very difficult to see, but this represents a three-part document that we wrote with our NICU to best care for patients preoperatively before they underwent the Norwood procedure.
Most importantly is this central?
Depiction where we identified patients.
Who might not fall into typical risk categories and might need extra support.
We wanted to make sure that patients had balanced circulation on optimal oxygen delivery prior to surgery.
We were focusing on minimizing morbidity.
We wanted to optimize nutrition and oral feeding before surgery.
Support them with development and parent bonding and recognize again those high risk factors. Those patients that were born early, small, a genetic anomalies had restrictive atrial septum.
At abnormal function or coronary anomalies.
Dillon.
Through formalized inpatient roundings for all of our single ventricle and high risk patients with our 12 member team, we were able to act as a support system to the primary team and build separately for focusing on these patients care. We started initially seeing one to three patients a.
Week those who simply had a Norwood procedure and quickly grew to well over 12 patients in a single week.
We focused on early readiness for feeds.
Starting neural developmental assessments early on in the ICU.
We looked closely at the patients in the cardiac ICU who were felt to be stuck or needed greater continuity and improved communication, and once they went to the discharge unit, we focused more on discharge readiness, parent education and preventing readmission.
This is at chart which looks at the days between unexplained unplanned readmission rates for the first year following our institution, starting the home monitoring program and prior to hiring a nurse practitioner to monitor these patients on the outside.
The higher the graph line indicates a greater amount of time between unplanned readmission, as seen on the Y axis for each patient in the home monitoring program.
The second T chart looks again at days between unplanned readmission, but this

time it was after our nurse practitioner had joined about five months.
And we can see there's a dip which represents when we instituted home monitoring calls weekly to check in on the families.
With this, before our, our families had a nurse practitioner to reach out to and after in 2022 we saw there was over a 65% reduction rate in critical readmissions. While the actual number of readmissions per patient went up from 1.1 to one.
.3 most patients were now being admitted to the floor.
Did not require significant oxygen support or vasoactive support.
This was considered a win.
Next, we had to focus on developmental outcomes.
Again, going back to our risk mitigation, there are several things that we can focus on while the patient is in the hospital to really focus on development and long term care for these patients, we can look at decreasing stimuli, clustering cares, non pharmacological measurements to comfort the patient.
Other than just medications for pain control, we can follow infant cues for feeding, skin to skin and maternal bonding. Infant massage and early mobility from a therapy standpoint.
Children with congenital heart disease are more likely to experience developmental delays than the general population.
In fact, this is the most common associated outcome with patients with congenital heart disease.
All aspects of development are affected.
This includes motor, speech, behavior, learning, social, emotional eating.
There's also a higher rate of mental health disorders, including anxiety, depression.
Obsessive, obsessive compulsive disorder and psychosis.
This is likely multifactorial.
The brain begins to form differently in the fetus by the 3rd trimester, in severe forms of congenital heart disease, early in infancy and toddlerhood, we see significant motor delays, which has been well documented in the literature.
Pervasive development disorders are common in toddlers and early school age children.
They may exhibit autism with repetitive body movements, unusual toy play, difficulty interacting with others, or difficulty using or understanding language with extreme responses to loud noise.
It is also common to see differences with attention learning disabilities. About 15% of

school age children will experience these symptoms and up to 20% will have behavioral concerns in patients with single ventricle congenital heart disease, as many as one third will require remediation at a school.
Grade and adolescents may have higher rates of memory deficits and increased rates of remediation.
In adulthood, they have lower education, lower occupational levels and compared to their healthy peers, have overall lower quality of life scores.
So preoperatively, preoperatively neonates with congenital heart disease are already at risk.
Most common brain injuries are those of white matter and focal strokes. Up to 40% of patients before surgery have evidence of brain injury.
This is due to hypoxemia time and weight to surgery pre operative based deficits, cardiac arrest and the need for a balloon septostomy.
Postoperatively patients are risk for low cardiac output hypotension, which can lead to new white matter injury, hypoxia, timing to surgery, again brain immaturity and neurotoxic chemical exposure.
I know this is a big graph and again a little bit confusing to see, but what we wanted to look at was how again can we mitigate these risks?
We looked at the number of therapy sessions.
Our patients were receiving while they were in the hospital. Most of our patients were receiving therapy only one to two times a week. Despite their prolonged hospitalisations. For some, as long as six months.
We know that patients with single vitrial heart disease are at high risk, but we could focus on this and we could work to improve this with the help of our therapists.
We set a goal for all patients who had hypoplastic left heart syndrome to see our therapist three times a week.
What we found in the first nine months of recording this was we were very limited on the number of times that patients were actually seeing three times a week and as opposed to the standard of two times a week, anytime you see yellow in this graph is when.
We hit our goal.
We use this information to say to our leadership that we were not having enough therapy opportunities and to leverage hiring additional practitioners.
Yes.
In the meantime, when we are waiting for those changes to be set, we worked on

nursing education and parental education to focus on development at the bedside. Each patient has a developmental goal sheet hung at their bedside, focusing on speech, occupational and physical therapy activities that the nurse or parent caregiver can give when the therapist is not available.
Lastly, we set out to improve handouts and family education, as well as implementation of emergency action plans for our patients.
This is an example of our inner stage discharge checklist.
This is hung again on the patient's door when they are on the floor nearing discharge, our team takes charge in checking these off with the families at bedside, looking at their feeding practices, medications, screening and safety, as well as any additional.
Means that they may have before we can check off that they're officially ready to go home.
In each patient's discharge note, they have a list of guidelines that must be completed by the team.
They must have the visible checklist as shown previously.
They must have we gained for over 48 hours.
They must not be on two beats for longer than an hour.
Again, the risk for aspiration is high.
They must have medications no more than every frequently as every eight hours to accommodate patient lifestyles. They must complete a 48 hour rooming in process with nursing documentation.
And they must consult our pediatric psychologist for additional support.
Additionally, we have follow up plans as per the patient's diagnosis.
This is an example of a wallet card that we send home with our patients so that if the patient is not close to the Vanderbilt system and goes to an outside emergency room, they are not forced to remember everything about their child, but simply can hand over a.
Card that they can keep in their wallet that states with the patient's basic oxygen level should be and what high risk factors should be?
It also gives a number to us that we can be communicated with easily.
This is an example of an educational checklist that we teach the families before they go home again focusing on Red List, a red flag checklist, as well as providing our contact information so families always know how to reach us.
In fact, we put our phone number in their phone so that it can never be lost.

Lopez is the home monitoring program that we use to track our patients outside of the hospital. It looks at things like oxygen saturations, heart rate.
The baby's weight over time.
The amount of intake they're using, whether that be via nasogastric tube or orally.
It looks at the percentage of oral intake they take and any concerns that the family might have.
This is set up to alert us on our hospital phone in case the family inserts any concerns.
Here we made it through phase one.
We were able to build a single ventricle team within the first six months.
We increased billing through inpatient rounds. We identified a network of patients through NPC Qsc.
We gain trust from the ICU and Cardiology colleagues, as well as our NICU and the families being there before the patient was even born.
We enhanced communication with the outside cardiologists, their primary cardiologist and pediatricians, and we overall improved continuity of care for patients and their families.
It was time to move on to stage 2.
We felt like we were spending so much of our time on the inpatient side.
We really wanted to focus more on the outpatient side.
So we started a single ventricle click.
Here we started seeing patients about four to five once a month, reserving spots for inner stage patients specifically and those to be considered the most high risk when patients were ready to go home, we worked with our discharge coordinator to schedule multiple appointments on the same day to.
Ease transitions with families. We had monthly clinics where we coordinated rides, provided gas cards and scheduled same day return visits for other subspecialties.
We additionally provided additional sub specialty referrals to the Vanderbilt system.
If needed, we enrolled them in Tennessee. Early interventions, which is a home system by which they can receive therapies.
We discussed the possibility of tube wing following stage two and we created patient surveys to assess how patients like to clinics looking at how far they had to travel, how long they felt the clinic days were, what they found positive, which included therapy, multidisciplinary appointments, attention to detail.
And the all inclusive care and how driving this far could be a complicated process.

We advertised using a sheet.
So that patients would know what to expect, when to see us, and we devise a chart for how patients would move through the day to make it most efficient.
We've been so focused on the patient as appropriately so.
But what we were seeing was that the parents were also suffering and we wanted to make sure that we could best support them.
Doctor Wroblewski is our resident psychologist.
Who is amazing and excellent at working with our families?
There have been several studies that have shown that caregivers.
Have a higher confidence and knowledge after discharge when actively participating in the care of their infant.
Many caregivers still feel anxious with the transition from inpatient to home stress, anxiety and depression may increase when barriers to education are present and researchers are low.
This is very common in the state of Tennessee.
Interstage home monitoring teams can lessen those factors through participating in home needs and validating the caregivers stable trends.
Additionally, greater than 80% of parents with children who have complex congenital heart disease have symptoms of trauma, 2550% had depression or anxiety, 30 to 80% have psychological distress, and this increases the risk for attention deficit and hyperactivity disorder.
So with this and the help of Doctor Wroblewski, our pediatric psychiatrist, we have patients in the cardiac ICU fill out the impact of event scale or the IESR which is a self reported measure to assess subjects distress and trauma caused by being in the ICU or having a.
Child with congenital heart disease.
It looks at risk and protective factors and symptoms associated with trauma.
It's a 22 item self reported measure.
Where items are reported on a scale of 0 to 5.
In our study, we included 27 patients over the first year. Patients who score greater a score of greater than 24 out of the mean score of 28, which ranges up to 56, were considered to be high risk for trauma.
These scores then prompted an inpatient referral to Doctor Wroblewski during their hospitalization for assessment of their mental health needs.
What we found was that parents reported the most common trauma associated

symptoms as intrusive thoughts, waves of feelings which were experienced in over 60% of our parents.
In this first graph in on the right on the right.
Excuse me.
On the left, we look at parents who reported their primary stressors.
Parents identified the initial diagnosis as their most impactful in contributing to their levels of distress seen in nearly 50% of the parents, followed by a long hospitalization.
The second graph in green represents the most common parental self reported psychiatric history, generalized anxiety disorder, or gad, and panic disorder was by far the highest.
In 40% of patients, when present, it led to an increased trauma. Symptoms score on the Iesr in future, we hope to use this information to help identify stressors which could serve to target metrics for intervention and under score the need for integration in trauma informed services prior to.
Discharging our patients and families.
Next, we really wanted to focus on early inpatient neural developmental assessment.
Given all the delays that are known about high risk factors for these infants, we wanted to focus on this even before they were discharged from the hospital.
This is an example of the neural developmental assessment using the Daisy or the developmental assessment in the young traditional neural developmental testing in any patient typically takes place at six months and older.
Our developmental follow up program really wanted to focus on patients between.
The first few months of age, we use the Daisy tool to capture a child's patterns of strength and challenges. Based on caregiver interview as well as child observation with one of our two psychologists, the parent and caregiver were interviewed and completed by the psychologist, which inquired about.
The child's functioning across 5 areas of developmental domain.
This includes cognitive functioning or problem solving, communication, understanding and sharing information.
Social emotional skills, physical development. These are motor skills and adaptive behavior, which is feeding mostly in the in the infant.
Here we looked at 20 patients over the course of our first year.
Patients were aged a medium median of 60 days.
Six were pre term less than 37 weeks with a median weight of 3 kilograms, 55% were

male, 80% were white.
Three had a genetic anomaly.
And two required ECMO and two had to strip most patients that were reviewed underwent a Norwood Sano, about 45%, followed by 20% who had a BTT shot.
Here we saw that 50% of patients were below average or lower in the general developmental score. 70% of patients have delayed adaptive behavior, 1/3 showed delays in cognitive, expressive language and social, emotional and 2/3 showed physical developmental delays in gross motor skills, which is.
A well known finding in infants and toddlers who have congenital heart disease.
Lastly, for our end of year goal too, we wanted to focus on two winning and getting to know these families.
Feeding became the utmost concern for most of our parents and this is a variable that we knew we could improve.
1st we created a smart aim to increase the percentage of oral intake compared to those who are just Ng feeding.
With this we created a key driver diagram using regular use of feeding protocols, focusing on gastric instead of intestinal feeding and focusing on speech therapy. Use while in the hospital.
This was more challenging than we thought.
So instead we pivoted from our inpatient to our outpatient protocols.
We focused on two weaning after the second stage surgery. Patients were seen in our multidisciplinary clinic four, six weeks after their stage two or when medically stable.
Our guidelines included cardiac stability, a safe swallow study, demonstration of growth on their current plan, communication with the pediatrician and family's readiness or fear about two weaning had to be addressed.
We evaluated these patients weekly or every other week, sending them home with a scale and meeting them over telemedicine to assess weight gain.
With family permission, these are two of our now toddlers who eat all by mouth, sharing their first birthday stories with us.
We have graduated over 14 patients from this program at this time.
We made it to pH phase two by the end of the year, we had instituted a single venrical clinic.
We now screen and recognize parental trauma in the cicu.
We start early developmental screening while in the hospital and follow them

through the outpatient side before stage 2.
We've established a feeding tube weaning program following stage two and we're ready for stage 3.
Stage 3 we really wanted to aim on focusing on academic projects, forward thinking about developmental programs.
And Qi initiatives, both in the CICU and the floor, we wanted to decrease hospital readmission rate.
We wanted to join the NPC, QIC or cardiac neural developmental Outcomes collaborative to be a more active representation from Vanderbilt, and we wanted to focus on family and patient bonding and interaction.
Perhaps this means a single ventricle day with our families in the future.
As of today, we have now expanded our clinic to two times a week and increased our presence via.
Medicine for our families who live three to five hours away.
Oops, this is an example of our team.
Sharing all of their hard work at the last cardiac neural developmental Outcomes collaborative meeting, I am so lucky to work with a team that is this wonderful.
Thank you for your time and I'm happy to take any questions.

Kamat, Deepak M 44:57
Thank you Doctor Colombo, with a wonderful presentation on how to build a single ventical program.
There is a common thread. After Verbena, we have a single ventricle program at Pediatric Health Center at University Hospital I think.
Which opens every other week. Our patients are discharged home with home pulse ox and scale.
And we also have.
App I think to follow up the patients.
Yeah, to to have families.
Track waste and feed and oxygen saturation and heart rates.

CN

Colombo, Jamie N 45:32
Yes, that's wonderful.
I think it's been established to help patient interstage survival and drive barbenell, and I have talked about this offline many times. That's great.

Kamat, Deepak M 45:43

This question by Doctor Williams please describe how you have integrated and coordinated positive and post Nasu follow up and the primary pediatric care and visit. So there is continuity of care on those two levels.

CN

Colombo, Jamie N 46:00

Yeah. So this is a multifactorial. So our NICU follow up clinic typically starts between six months and a year of age just because of the vast number of patients that they see, which was really nice because we found that they that our focus was mainly on those child.

That were less than six months of age during that inner stage period.

So our psychologist for any patients that we have.

High concerns about actually do a a hand off with our NICU provider.

Who also do our development clinic from that one to three-year time frame before the child is before their development is focused on school. And so we are in close contact with all of them.

We have had multiple meetings with them to discuss collaborative care and all of our patients are referred to the NICU follow Up clinic.

It's been a great working relationship as far as our pediatricians go, so.

Our pediatricians receive weekly updates.

While the patient is in the hospital so that they are up to date on what is going on and when the patient might be nearing discharge, they receive a one page letter that kind of highlights what the main complications or problems that are going on and this is.

Also sent to their outpatient cardiologist when the patient is ready for discharge.

One of our two nurse practitioners will call the pediatrician and give them a verbal sign out and answer any questions they have.

This is followed up by a one page sheet that talks about what hypoplastic left heart syndrome is and what the inner stage.

Here it is.

And what the pediatrician should specifically be looking for?

And then all pediatricians are communicated with again, once we see them in clinic as follow up for any risk factors that we might be observing.

Kamat, Deepak M 47:45

Thank you, Doctor Abarbanell, we have question.

Please go ahead and ask your question.

Abarbanell, Ginnie L 47:49

I just wanted to put this out to the folks here at Grand Round, so I run the single ventricle program here. I started it.

Probably I took it over about a year ago from our cardiac Cath doc, who moved to Michigan, but we're always looking for really interested primary care providers.

I like that question that Doctor Williams posed to partner with us on these types of babies because.

The PCP is really an integral part to taking care of these babies.

As well.

And then the other thing I put in the chat, just so people know, we did have our second Kids heart camp in April and we had a lot of single ventricle kids out there doing zip line and doing all kinds of really, really great activities that they wouldn.

Get to do otherwise, but got to do some of the stuff that normal kids do.

Colombo, Jamie N 48:40

That's amazing.

That's great, Janet.

Yeah, we partner with.

A different portion of our NICU program, where we have a primary pediatrician for all kids enrolled in the single ventricle program who are in the Nashville area, will follow one pediatrician, and then we have a list of pediatricians who enjoy caring for children with congenital heart disease based.

On where the families live and will often contact them before discharge to see if they'd like to take on another patient. So.

Ia 100% agree with you that.

The pediatricians are a huge, huge part of caring for these patients during this high risk period.

Kamat, Deepak M 49:18

Is a comment by Doctor Gong. Our Nic follow through care starts at 3 months to capture early cerebral palsy diagnosis.

Colombo, Jamie N 49:29
That's wonderful.
That's great that you have the capacity to start so early.

Kamat, Deepak M 49:36
Any other questions, comments. Sorry.

Williams, Janet F (Dr.) 49:36
I was.
This is Janet Williams.
Thank you for that wonderful presentation.

Kamat, Deepak M 49:40
Yeah.

Williams, Janet F (Dr.) 49:43
I was interested in also continued.
Dialogue of report so that for example.
The cardiac team is aware of the developmental follow up that the pediatrician does as a routine and the vaccines and the various things from the.
General pediatrician's standpoint to make you aware as well or if you're already doing like the ECI referral so that both parties are are a team as well.

Colombo, Jamie N 50:20
Yeah, absolutely. I think we found that our general pediatricians are so incredibly busy.
I mean, they care for so many patients that for the patients that follow with our single ventricle program or or in our NICU follow up clinic.
The the NICU follow up and our team really takes precedence of the the early developmental follow up at least through the age of 3.
That's just kind of how it has seemed to work out, but I agree with you that the pediatrician.

Can be a huge part of that, especially if that's one of their interests and it is another way to get families resources that they need because it really does take a huge team to to get these families everything that they need, and especially when they live in R. Areas we may not have as many resources to get them into the patient's home or find out which, you know, therapists might be best or most interested in working with complex kids.
So that's a great point.

Kamat, Deepak M 51:21
Other question comments for Doctor Colombo.
Doesn't look like this.
Thank you Doctor Colombo, for that wonderful presentation.
Thank you all for attending this morning's grand rounds.
Just a reminder that this was the last grand round for academic year 202425.
We'll meet again on July 18th.
We have 4 weeks of break from grand Rounds and we'll see you on July 18.
Thank you again for attending.
Thank you, Doctor Columba. Appreciate it.
I'm going to conclude this morning's round.

Colombo, Jamie N 52:09
Thank you so much.

Kamat, Deepak M stopped transcription