

**NASUH MALAS:** So just before I start, just a show of hands of folks in the room who have ever provided care for somebody with functional abdominal pain. OK, almost everybody. How about chronic headaches that are disproportionate? Or I don't even have to say it.

Epileptic seizures, nonapoplectic events? OK. Yeah, so about 60% to 70% of you. Up to 100% for some of these conditions.

These are the types of conditions that we're going to be talking about today, and is the basis of a lot of work we do at the University of Michigan. I'm also involved in a national group that's developing clinical practice guidelines for this set of conditions. What's critical for this set of conditions is the language. And so we'll be talking about language and how we can provide a framework for evaluation and management of somatization.

So a little bit of background. So what is somatization? So when you think about the word somatization, we have a lot of historical language. Dr. Brabender reviewed the DSM. There used to be something called somatization disorder.

I don't know if any of you recall any of that, but you had to count symptoms. And there was know certain pain symptoms, sexual symptoms. And it just seemed like such a terrible task to do. Well, with the DSM V we've done away with that. When we say somatization, we're talking about subjective reports that patients provide of physical symptoms that are either disproportionate or inconsistent with physical etiology.

So this is a patient who comes in, and their report of symptoms does not match up with the evaluation you're obtaining. It is not a condition where you haven't found the cause yet. So it's not a diagnosis of exclusion. And that's very important to be aware of. Somatization is very common.

So we all know the child that comes in with stomach aches because they had a stressful event, headaches, because they have to give a presentation or perform in front of other people. The prevalence of somatization as a component of a primary care visit, up to 50% in most studies. A very common issue, but typically is not impairing results with minimal to no intervention. Then we start talking about somatic symptom and related disorders.

So this is the new DSM V category. This is an umbrella category of somatization that becomes

impairing, recalcitrant, persistence, and results in a significant impairment and dysfunction for the patient and often the families and often for us too. It's a point of significant frustration as providers. It does not require the identification of another Axis I psychiatric condition.

So you don't have to be anxious. You don't have to have an identified stressor. You don't have to have depression to qualify for this condition. It can occur in the setting of another physical health condition.

So if you have inflammatory bowel disease and you have functional abdominal pain that is not consistent with what you're seeing in terms of the control of their inflammatory bowel disease, that may qualify for this condition. And the prevalence in inpatient settings-- that's where I work-- is 13% up to 15%. And we'll talk about the impact of this condition on readmission rates and utilization.

So the DSM IV, a lot of terminology. I want you to forget about all that. I just list it here so that kind of orients you. The rationale for the change with the DSM V that was developed in 2013 was this language, did it makes sense? Just like Dr. Brabender discussed in his talk, if you overly focus on ideology-- and that's what happened with the DSM IV TR-- people were focused on identifying stressors or psychological distress.

Half of these families as we know will say my child is never stressed. There is no stressor. There is no issue. And it results in a conflictual relationship that's not productive. And what we know from the pathophysiology and learning more and more about this condition is that it's not really about identifying a stressor.

And some of these kids don't have one identifiable stressor. They may have chronic stress. They may have some other reason for biological priming for this condition. So that's been done away with in the DSM IV. The terminology has been simplified.

So just like Dr. Beerman said, we used to count symptoms with abuse and dependence, and debate between abuse and dependence. We've done away with that. And we've done away with somatic symptom and related disorder. And most importantly with working with families, we've done away with the stigma when we talk about this condition. And we'll explain how that happens.

So these are the typical conditions you're thinking about when you're thinking about the DSM V. Somatic symptom and related disorders is the umbrella term. The most common condition

underneath that umbrella term is somatic symptom disorder.

And to qualify for somatic symptom disorder, you have to have a symptom or symptoms that is either inconsistent or disproportionate to the physical exam history and clinical findings that you have. And usually is persistent for six months. And they specifically put that specifier in to prevent providers from jumping to somatic symptom disorder too early in the process. Because the last thing we want to do is assume it's a somatic symptom disorder when we haven't done judicious evaluation.

Illness anxiety disorder is similar to hypochondriasis. It's the idea of perseverating about a physical symptom when no physical symptom can be identified to organic disease. Functional neurologic symptom disorders a term that is now being advocated for instead of conversion disorder. So the term conversion disorder is a Freudian term. And it was developed with the idea that you're converting a stressor into a neurologic symptom.

A lot of families find this pejorative. They find it stigmatizing. They don't like it. And they feel like you are calling them crazy. And so what we wanted to do is be very descriptive in general, and not really look at trying to identify an ideology in our language.

And like I said before, this is not a diagnosis of exclusion. So you don't have to work them up and do every single test when it's clear that the symptoms are not consistent with the evaluation. So if a kid comes in and has an abnormal movement, they've gone through a proper evaluation. They may have seen a neurologist, gotten an EEG, an appropriate physical exam and a prudent work up, you don't have to get an MRI on every single kid if they have no focal neurologic symptoms that would be explained.

So that's the big thing is that it's not you've worked up everything and this is what exists, because that's what families often believe. Is that you haven't worked up their child enough. And what's important to explain with this condition is that yes, we've gone through a prudent evaluation, but your child's symptoms are inconsistent or significantly out of proportion to what we're finding.

So an example would be I was in gymnastics. I tripped over and now I can't use my right leg. You go through your prudent evaluation. But that type of injury is inconsistent with complete loss of function of an extremity. And that's important to think of.

We know this condition causes a lot of impairment for patients and families. It causes a lot of

lost work and lost school time. The cost utilization, up to 20% of health care utilization is in relation to some component of somatization. And the most common concerns we already discussed. Most often abdominal pain, headaches, pain in other regions of the body, but also other neurologic symptoms, whether it's weakness or abnormal movements, seizures or attacks, and then fatigue.

This is a study that was conducted out at Boston Children's in 2014. Just to give you a description of the common child with this condition. Often, these children are presenting again, with neurological pain symptoms, but what's interesting, if you look at the study, a lot of these kids actually didn't have an additional primary Axis I disorder.

So not all of them had depression. Not all of them had anxiety. They did stay in the hospital for a long period of time. At our institutions, sometimes before we started enacting some of our protocols and guidelines, up to three four weeks at a time. The readmission rate for children with this condition would be up to 14% to 15%.

But these children are often shy avoidant kids. They are not the kids that are going to tell you that they're stressed. They tend to be more internalizing. They don't tend to express themselves as much. They tend to be described as good children.

So how could this symptom occur to my child when my child is a straight A student and they're performing very well? And there's a lot of significant academic pressures in school absenteeism in this population. Parents and families feel frustrated. They feel dismissed, unheard. They feel that something serious is going on and is being missed.

They feel that you have not done enough. And they feel that they need to advocate for their child because they don't have a functional framework for understanding why their child is decompensating and presenting with physical symptoms, particularly when they're being told your child is stressed. They have anxiety.

No my child is not. You don't understand me. You don't care.

These are actually some quotes from families we've worked with. "Every doctor has given up on my child. I'm not giving up on her." "You have to stop thinking in the box, you have to think outside the box." So there's a strong advocacy from parents to want to find the cause.

And providing normal findings is not reassuring for these families. They tend to want more. And they tend to travel if they feel like they're not getting the response that they want.

In primary care these patients and families can be time intensive. They often are nuanced and have a variety of complex factors that contribute to their care. There's a lack of referral sources, and we all know that it's very difficult to access mental health providers in the community. And there's a mismatch between the patient needs and the systems of care. And so what we see is that a lot of providers become avoidant, they become dismissive, or they even can start to have significant conflict with families.

This is a diagram from the University of Utah just to show how complex this condition is with a lot of contributing factors. And so the key thing in talking to families is these conditions are often multi-factorial. We talked about the temperamental style. Children who are perfectionistic, who are shy, who are pessimistic, who have a passive coping style, who have kind of passively dealt with chronic stress tend to develop this condition. We tend to see it more in younger children, but it becomes more pathologic in older children.

Females tend to have a higher prevalence of this condition at later ages. There is a biological underpinning. And what we know with these kids is a lot of them have something called somatic sensory amplification. So they perceive sensory stimuli to have a much more heightened alarming response in their brain in the frontal cortex in the somatic sensory cortices. And they tend to overreact to those stimuli.

So they are actually experiencing the symptoms, but their response mechanism, the connections from their body to their brain are providing that response. And so we talked about the rehabilitation approach before. That's the type of language we want to share with families that we are going to rehab that body in that brain so that they are working better together, and that we kind of turn that alarm off.

And a lot of times I use the analogy of a car alarm. So a nonfunctioning car alarm, initially when you hear it, you think that there's somebody breaking into the car. When it happens for the hundredth time, we know that the car is not functioning.

There's the wiring or the process of that alarm is not due to somebody breaking into the car. But when you're experiencing that as a child, you can't tell that that alarm is alarming inappropriately. And a lot of times using analogies like that to make it kind of simple for families can be helpful in explaining this condition.

Children with physical illness can be conditioned to develop physical responses to stressors.

And to just generally non-stressful situations, they can be primed. We know that kids with seizure disorder, about 2/3 of them will develop a epileptic event during the course of their lifetime.

We also see a dichotomy in children where children who are very high functioning tend to have temperamental styles and coping styles that may result in them being at risk for this condition. But also children with lower IQs and lower capacities to deal with stress may also be a higher risk. So we see that difference.

One thing that's very different in children is trauma. So a lot of times we think if a child is manifesting somatic symptoms and declining, there must be some trauma. There must be some significant adverse event that occurred. This is true in adults.

But what we found-- this is a study out at Boston Children's again. They tend to study this disorder a lot. In 2015 where they looked at the association, they found that it was actually the same in the general community, and there was not an association with trauma. What's important about trauma and identifying trauma in a child with somatization or somatic symptom and related disorders is that it modulates their progression.

So children with trauma tend to have more psychiatric comorbidity, tend to have more extensive psychiatric treatment, tend to be hospitalized either medically or psychiatrically because their conditions tend to have stronger family histories of mental illness, and also family conflict as a relation of this disorder. And trauma seems to hyper-attune or cause a hyper-vigilant state that children are more likely to respond with physical symptoms because of that traumatic response and the strengthening of the HPA axis and those trauma centers in the brain.

And this is the study, actually out at Boston Children's kind of explaining that. So we know that a lot of times there's not a great framework for evaluating and managing this condition. And that variability can cause a lot of frustration for families and for us as providers. The evaluation should be multidisciplinary.

One of the things that families often say is well, you've done the work up and now you're handing me off to psychiatry. That feeling for families and that feeling for patients is that you are dismissing how distressed I am, how difficult this is. You don't know what's going on and you're handing me off to a mental health provider because you think I am crazy. That's what families will tell us.

And so what's important is when you're providing the care and you start to have a concern that this may be going on, you may want to get a psychologist, a social worker, or a psychiatrist involved early to normalize that experience as a multi-disciplinary team that's providing care for a multifactorial condition with a rehabilitative approach. This is normalizing language and allows families to understand OK, now I know why I'm seeing the psychiatrist, because this condition is complicated and requires several providers. You want to focus on functionality and not disability.

These patients and these families want to tell you how bad everything is. I can't go to school. I can't do this. And so what you want to focus on is how can you do the things that you need to do to function, rather than how much impairment do you have.

Family involvement is critical. A lot of times families are engaging in behaviors that are permissive, that are allowing that disability to occur. So it's important to get families as partners in the process and help with limit setting of regressed behavior, and providing empathic small steps to again, that rehabilitative approach to allow the child to progress in their care. And again, you want to allow the school and obviously the PCP to be partners in this process.

So subspecialists, PCP, outpatient mental health, the school all have to be collaborating together in helping support this plan. Because if there is one member of that team that is not providing that consistent message, families will split that team. And so that is a critical component of treatment.

And again we talked about eating disorders, is it psychiatric? Is it is it physical? It's the same thing here. Is this an organic condition? Is this a psychosocial condition?

Well, the evaluation is ongoing and collaborative, and it occurs simultaneously. And even if you identify that the child does have a physical health condition, you have to determine, does that explain all the symptoms that the child has? But also that physical health condition may have some psychological or psychosocial component that may benefit regardless. So just because you're going through this process doesn't mean that if you identify other organic disease that the child can't or the family can't benefit from that psychosocial evaluation.

Screening, you have to be mindful that parental and youth symptoms don't correlate well. Surprise, surprise. So a lot of times you have to get multiple collaterals. And that includes

school, the PCP.

Sometimes these families may also have pathology within the family. There may be some enmeshment or some other factors that are driving symptoms. So getting those other collateral pieces of information are important.

These are some screening tools. They're used in protocolized in-patient settings, they're used in specialty centers. They are not commonly used in practice out in the community. But just to be aware of them, I've included them here. They can be valuable in providing another metric to monitor progress.

And then it's important to provide education to enhance that relationship with patients and families early. Start by talking about what the patient and family is experiencing. Try to target those emotions, and discuss how difficult it must be for the patient family to see their child decompensate. Talking using physical language, so talking about biological and physical illness, for a lot of families is helpful. And then as they're buying in and engaging in the process, you want to transition and include a broader picture where you're talking about psychological factors and stressors.

To start off by talking about psychological factors, which a lot of providers do with good intentions, can often lose families. Because it then seems to them that you are dismissing what they're saying. And so you want to ease the family into that process. And then you need to provide an explanatory model.

And a lot of times what I tell families is I can't provide treatment and management until we can identify the issues at hand. You have to identify the problems and then define the solutions. So we're not going to give you six different meds. We're not going to go to surgery. We're not going to send you to the hospital, unless it's obviously indicated.

But we are going to define what those issues are, and then build our treatment plan based on those issues. And that may include physiologic issues. So a lot of kids with this condition may need treatment for gastroesophageal reflux. They may need treatment for constipation. Again, it's multi-factorial, so it may include physiologic issues.

So this is what families are often told. We've got good news. The tests are all normal. So we know this is your child's body's way of dealing with stress or anxiety. We'll give you a referral to psychiatry.



So you can imagine hearing this as a parent. You just put your kid in for abdominal pain, and this is what you're told. This is not reassuring. This just feels like you're being sent out the door, and people are not believing what's going on.

And so just explaining findings as being normal or negative is not reassuring. And again, that handoff to psychiatry is something we want to avoid. We want it to be collaborative. And we want it to be normalizing from the beginning.

And then when you present the findings, it is helpful to do it in a multidisciplinary fashion. So what we do at the Children's Hospital is we sit down as a team, and all of us present the findings, including the physical findings and why we are not concerned about seizure, why we're not concerned about cancer. We go through that process and we explain it together as a unified team. In your office you can have somebody call in, whether it's the psychologist or whoever's involved, if there's a school personnel, and do it collaboratively. even if it's a call in or in some way.

You have to know your systems and know what you're capable of doing. But doing this in a collaborative way where the language and the conceptualization is consistent is key. And again, using visuals, using analogies, something concrete, these are abstract concepts for families to understand.

They come in with an infection, their child gets an antibiotic, their ear infection is resolved. That's a simple linear process. But having this kind of vague, complex, multifactorial issue can be very distressing for families to really comprehend.

So this is a model again, out at Utah where they actually put the symptom in the center, and then they provide this five pronged approach where they talk about the behavioral, physiologic, functional, social, environmental, and psychological factors that are contributing. And you can use this with any condition. And even non-somatic symptom and related disorders can fit within this diagram. But the idea is to visually represent what this looks like.

This is a handout that we give families at the University of Michigan providing some guidance as to the thought process we have, but also priming families to the idea that we are going to review the records. We are going to obtain information from collaterals. And these folks, including mental health providers, may be involved in your child's care. And the first thing we need to do is get a diagnosis or diagnoses, communicate those diagnoses to you, and have a

clear understanding of what we are treating.

This is a letter we sent PCPs at the University of Michigan, templated so we can incorporate that information. Again, that communication is key. And then in terms of the management, again, family engagement is critical. Families have to be on board.

You cannot move forward unless families are on board with the diagnostic conceptualization and the treatment plan. The treatment plan is rehabilitative. So the idea of having small progressive steps where we're addressing all the factors in play. And the PCP has a critical role. And one of the things that's most helpful in these conditions is to have regular proactive scheduled visits with the patient.

These patients and families tend to come in crisis. They tend to come when symptoms are exacerbated. And you want to preempt that and provide reassurance, and then if judicious evaluation is needed, you can provide that scheduled paced measures. And then you can space out the visits as needed.

In addition, psychotherapy is a critical component to the management. What we know is that CBT, cognitive behavioral therapy has moderate effect sizes in terms of managing these symptoms. But the CBT that's provided involves a lot of semantic discussion, so biofeedback, hypnosis, relaxation.

So again, helping the child understand how their mind and their body is connected. Helping them gain insight. And helping practice techniques that they can use in real time to be able to manage the symptoms. Identifying what factors in the care are providing secondary gains or resulting in decompensation, and then really having that ongoing collaboration between mental health and primary care. And that can be challenging a lot of times because a lot of mental health providers or other providers in the community may not be willing to engage.

So knowing your community resources and knowing the people that you can partner with. At the University of Michigan, we're starting to look at some educational resources and ways to help PCPs in the community to address management and troubleshoot.

Engaging the school, so helping the school understand that when the child is having a non-epileptic event, you don't need to administer Diazepam and cause a big stir and call the EMS, and have all the kids rush into the room. That is going to exacerbate that symptom. So helping schools understand the factors that may worsen a non-epileptic event, abdominal or chronic

headache that may be due to a functional process. Medications have a limited role.

So somatic treatments such as, like I said before, treating constipation or treating gastroesophageal reflux can be helpful, but they're part of the plan. And families will come to you wanting a quick fix. Give me that pill that's going to make my child better again.

And it's going to be very tempting to say here is Neurontin. Here you go. See you later.

Come back in two weeks, four weeks. You have to set limits with families too, and explain that this is not a condition that's going to go away with just one pill. So medications may be a component treating co-morbid, anxiety, and depression is going to be critical as well.

And then identifying the level of care. So if the child is so impaired that they are not walking, that they are not functioning, they may require inpatient level of care. But a lot of these conditions can be managed effectively in the outpatient setting. And the key is to address this early, and have close communication with the patient and family, again, with measured regular visits.

This is a model that we published just this year of all the factors that contribute in the systems that are affected. As you can see, there are a lot of arrows and there's a lot of language on here. And you probably can't even read it. So this is a very complicated condition. And don't feel like you need to do this all alone.

But as PCPs, as community providers, you are at the front lines of this condition. And the tone you set, the language you set, the approach you take is critical as to whether a child develops a lot of iatrogenic injury, complication and issues, or dissolution of that relationship with the provider versus having a good outcome.

So here are some key points. What I really want to stress with this condition is that it starts with having a good connection and engagement with families. Helping them understand why it's not a brain tumor, why your child does not have a seizure. Going through judicious evaluation so that you do not miss something that needs to be addressed. But then once that evaluation is completed, including mental health involvement, a clear diagnosis needs to be made or diagnoses.

And then the communication of why the child may be developing those symptoms needs to be discussed, including the propensity for the child to develop those symptoms because their body is over reacting to stimuli that other children may not. And that is something that is

biologically based, can be exacerbated by psychological stressors, but not overly focusing on stress and anxiety as a root cause. And then connecting children and families to the right resources, including mental health providers in the community. Thank you.