Anxiety, Depression, and Hydrocephalus



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-I blame sitesolutions









- -It can hurt me
- -It's right next door, so it's hard to ignore
- -The door could open at any time, so it's hard to relax
- -I'm not sure I can defeat him



- -Maybe you don't live next door to something scary
- -If you do, however, there's probably nothing better than getting the rest of the neighbors together to share each others concerns









- -It's life threatening
- -It's right next door, so it's hard to ignore
- -The door could open at any time, so it's hard to relax
- -Maybe you're not sure you can defeat it the next time it happens







Let's open some doors (carefully)

What is the impact of living with a potentially lethal medical condition?

Pediatric Medical Traumatic Stress

We should consider if this is a potential problem



- There has not been much research (or related publications)
 regarding anxiety and depression in hydrocephalus
- There is a growing body of research, however, in Spina Bifida, with increased recognition of anxiety and depression among young adults with the condition
- Isolated studies have indicated that families may experience less stress when the individual with hydrocephalus has an ETV versus and shunt
- There's been more written regarding NPH
- An important thing we can do today is consider if stress, trauma, and anxiety associated with hydrocephalus (for the individual, parents, siblings) are issues that should receive more attention.
 - Facebook
 - Audience Polling

Pediatric Medical Traumatic Stress

An Integrative Model of Pediatric Medical Traumatic Stress

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- "Having a life-threatening illness can be traumatic for children and families at many points along the diagnosis and treatment continuum (including survivorship,) and can be impacted by perception of life-threat."
- "Perception of life threat is often unrelated to (objective) prognosis. Parents who believe that their child might die or children who believe that they could die can be at increased risk for persistent posttraumatic stress."
- "Parents and siblings can also be affected, even after treatment ends.
- "Most children and parents are able to cope well, with some extra support and with time."
- Some parents become hypervigilant for signs and symptoms that the illness has returned. Siblings may worry in private about their brother or sister.

- Treatment can be painful and emotionally difficult at times.
- Treatment setbacks sometimes occur, in addition to physical changes and limitations.
- Parents often feel helpless when they see their child in pain, and
 a child in pain can feel angry, frustrated or depressed.

- Phase I
 - Occurs at the time of the potentially traumatic event
- Phase II
 - Traumatic stress responses that occur after the initial event and treatment
- Phase III
 - Longer term traumatic responses
- May happen again and again
- Impacts patient, siblings, parents



- "My daughter is 4 and has already had 9 revisions."
- "My son has had 3 surgeries and he's 19 months old"
- "I am 36 and have had brain surgery 16 times."
- "We've spent 8 weeks in the hospital with my son in the past 18 months, and I wish we never had to go inside a hospital again."

"My daughter with hydrocephalus started waking up in screaming/crying episodes and they told me it was night terrors and behavioral problems. I knew something wasn't right! I kept pushing and they finally discovered a shunt malfunction that didn't have the normal symptoms. She later had emergency wound revision and I had to hold my child while they pulled the scab off her head and try to comfort the screams."

- "I got violently ill the last time my shunt malfunctioned, and by violently ill, I mean, I vomited NONSTOP!"
- "Seeing your child in so much pain is just heart breaking. The headaches are horrendous and no amount of pain killers work."
- "I had 3 malfunctions in my 31 years and all 3 time my mom was worried that I might die"

- "I was in a coma for 3 days on Christmas and one day last month because of a malfunction."
- "I found out my daughter had internal and external hydrocephalus the day before her first birthday."

Let's open some doors (carefully)

The diagnosis, treatment, and recovery from hydrocephalus can be a seriously traumatic event

It would be reasonable to view this as a life-threat



- Phase I
 - Occurs at the time of the potentially traumatic event
- Phase II
 - Traumatic stress responses that occur after the initial event and treatment
- Phase III
 - Longer term traumatic responses
- May happen again and again
- Impacts patient, siblings, parents

- -It's out to get me
- -It's right next door, so it's hard to ignore
- -The door could open at any time, so it's hard to relax
- -I'm not sure I can defeat it



"I'm always afraid the luck will run out..."

- Adult: "I always wonder if my next revision will be the one when things start going wrong"
- Parent: "I'm always scared that a shunt malfunction will change my daughter's personality...I'm always afraid the luck will run out"
- □ Parent: "I am always waiting for the shoe to drop."

"The next minute anything can happen..."

- Aunt: "My niece is just fine one minute, but the next minute anything can happen."
- Parent: "...knowing at some point the shunt will fail."

"I still get anxious with every headache..."

- Parent: "I still get anxious every time my son has a headache. His last revision was 8 years ago, but he had a brain infection at that time."
- □ **Adult:** "Headaches, nausea and not knowing if it's sinuses or virus."
- Teen: "When I tell my dad I have a headache, he gets this panicked face"
- Teen: "Everyone thinks I'm faking and the school yells at me for school absences."

"The constant guessing game..."

- Adult: "You never know when something is wrong. I've had 8 revisions and all my symptoms were the same so when I just have a headache or feel nausea I have to consider its my shunt instead of thinking its a cold or the flu."
- Parent: "The constant guessing game of whether it's a simple bug, or a shunt malfunction when my 4year old gets sick."

"The constant guessing game..."

- Parent: "Every cold, crabby attitude, or sleepy day my son has makes me nauseous. If he's at school and that phone rings I want to sink into a hole!!!!"
- Parent: "Only a hydro mom gets excited over a virus or stomach bug because she knows it's not shunt related!"
- Parent: "Whenever my daughter cries out in the middle of the night."
- Adult: "When my vision goes wonky...l always fear it's a fatal stroke..."

"The constant guessing game..."

- Parent: "I worry when my daughter says she has a headache or doesn't feel well, as the common cold carries the same symptoms as a malfunction."
- Parent: "Every irritable day my son has or if he tells me his tummy hurts sends my head spinning with the possibility of something going wrong."

"We are scared to travel..."

- Parent: "Fear of malfunction when we are traveling away from our neurosurgeon and children's hospital."
- Parent: "We are scared to travel by airplane."
- Parent: "Taking my daughter on a trip out of town is always stressful also because you never know when a seizure might happen."
- □ Teen: "I don't want to travel too far from my neurologist and neurosurgeon"

- "I worry we won't recognize a malfunction..."
- Parent: "Sometimes I worry we won't recognize a malfunction."
- Parent: "I worry if my 3 year old will be able to tell me if she doesn't feel right."
- Parent: My son will soon be 2 and he can't verbally tell me something is wrong. I watch for everything, if he coughs or sneezes wrong, if he sleeps too long or even if he throws up; I instantly think something is wrong."

- "I worry we won't recognize a malfunction..."
- Parent: "My daughter is only 6 so it's hard for her to express a malfunction from a cold or body ache."
- Parent: "My daughter has autism and is developmentally delayed so she can't tell me when or where it hurts."

"Will I wake up...?""

- Adult: "I won't go to sleep if I get any type of head ache. The last time I had my shunt changed I went to sleep on a Sunday afternoon with a migraine and woke up 4 days later in a recovery room not able to move my head and no clue where I was."
- Spouse: "Anxiety for our family is basically a daily worry. My husband has had numerous shunt failures and most have been without any symptoms before. He will go to bed feeling and acting fine and then will not wake up in the AM."
- Parent: "Everyday when she open her eyes it's a huge celebration."

"Will we get to the hospital in time...?""

Adult: "Not getting to the hospital in time"

"Will this MRI be normal...?"

- Parent: "The scheduled MRIs make my family anxious. You can feel the tension build until you hear that "everything looks good."
- Parent: "We've had many MRIs and some have not come with a definitive 'green light'. I wish I had an app on my iPhone that could tell me if my son is in failure."

"Will things get worse...?""

- Parent: "I worry about the long term effects. I wonder if my son will develop seizures, memory loss/function, cognitive problems and motor issues."
- Parent: "I'm always worried about seizure disorder later on in life for my 2 years old. It's just nerve wracking to me and it's in the back of my mind daily."
- Parent: "The unknown of my son's future. Will it malfunction?? Will he get an infection???"
- Adult: "Personality change after revision"

"Will I get lost...?"

- Adult: "I get lost very easily. The "mall cops" know my mother and me on a "first name" basis. ("Your son is here again..."). I got to where I would study maps. Over. And over. And Over. City maps. Bus maps. ANY map. Until I know it backwards and forwards. If a place ain't on the bus route, it doesn't exist (for me, anyway)!"
- Parent: "Sometimes my daughter's fine at knowing a place and other times she can't figure out where she is at all."

Let's open some doors (carefully)

The potential for "everything to suddenly go wrong" in hydrocephalus may fuel long term stress responses



Audience Poll

- Compose new text message
- Recipient is:
 - 22333



Re-Experience Symptoms

- Thinking a lot (unwanted, intrusive thoughts) about the illness, injury, or procedure
- Feeling distressed at thoughts or reminders of it
- Having nightmares and "flashbacks"
- None of these

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Avoidance Symptoms

- Avoiding thinking or talking about the illness, injury, or hospital experience, or things associated with it
- Displaying less interest in usual activities
- Feeling emotionally numb or detached from others
- None of these

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Hyper-Arousal Symptoms

- Increased irritability
- Trouble concentrating or sleeping
- Exaggerated startle response
- "Hyper-vigilance"— always expecting danger
- None of these

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Pediatric Medical Traumatic Stress

- "Many ill or injured children, and their families (up to 80%) experience some traumatic stress reactions following a life-threatening illness, injury, or painful medical procedure.
- "It has been reported that between 20-30% of parents and 15-25% of children and siblings experience persistent traumatic stress reactions that impair daily functioning"

Pediatric Medical Traumatic Stress

Traumatic stress reactions are common in hydrocephalus

Or

 Traumatic stress reactions are not common in hydrocephalus

Let's open some doors (carefully)

Recognizing these as traumatic experiences is a first step towards dealing with them



Pediatric Medical Traumatic Stress

Prevention Model:

Addressing traumatic stress in the pediatric healthcare setting

Clinical / Treatment

Persistent distress or risk factors.

Arrange psychosocial

and mental health support.

Acute distress or a few risk factors present.



Provide extra support and anticipatory guidance.

Monitor ongoing distress and refer if needed.

Targeted

Most children and families are understandably distressed but coping well.



Universal

Provide general support — help family help themselves.

Provide information regarding common reactions. Screen for indicators of higher risk.

Preventing and Treating Traumatic Stress

PMTS Toolkit for Health Care Providers

- National Child Traumatic Stress Network (NCTSN)
- Pediatric Medical Traumatic Stress Toolkit for Health
 Care Providers

www.nctsnet.org/nccts/nav.do?pid½typ_mt_ptlkt;

Assessment and Treatment of PMTS

D-E-F PROTOCOL

for Assessing and Treating Children and Families with Traumatic Stress

- DISTRESS See pocket card for brief assessment and recommended interventions to address and treat pain, fears and worries, and grief and loss. Recommendations include:
 - · Actively assess and treat pain, using your hospital's protocol.
 - Provide child with information about what is happening and choices regarding treatment decisions when possible.
 - · Listen carefully for child's understanding and clarify any misconceptions.
 - · Ask about fears and worries.
 - Provide reassurance and realistic hope.
- EMOTIONAL SUPPORT See pocket card for brief assessment and recommended interventions to address child's emotional needs, and barriers to mobilizing existing supports. Recommendations include:
 - . Encourage parents to be with their child as much as possible and to talk with their child about worries and fears.
 - Empower parents to comfort and help their child.
 - Encourage child's involvement in age-appropriate activities when possible.
- FAMILY See pocket card for brief assessment and recommended interventions to address parents' and siblings' distress, family stressors and resources, and needs beyond medical care. Recommendations include:
 - · Gauge family distress and other life stressors; identify family strengths and coping resources.
 - Encourage parents to use own coping resources or support available at the hospital or in the community.
- D E QUICK SCREEN See this pocket card to identify and assist those who have traumatic stress symptoms or who are at greater risk for traumatic stress. Recommendations include:
 - · Involve psychosocial staff in a team-based approach for those at higher risk.
 - · Make referrals to hospital or community-based mental health resources when appropriate.

OTHER See the charts on pages 7-9 for descriptions and information on useful clinical measures for assessing acute and post-traumatic stress symptoms in children and parents, as well as tools for assessing pain and parent coping assistance.

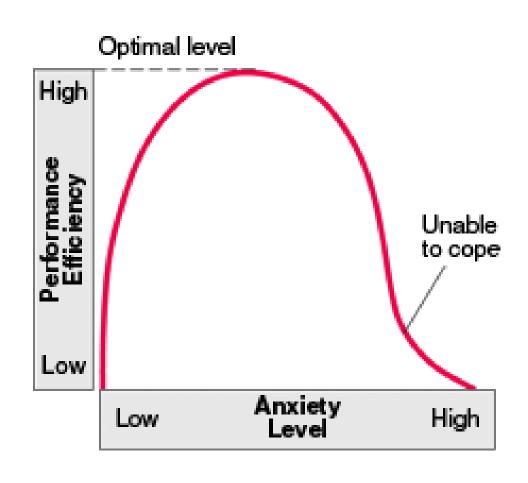
http://www.nctsnet.org/sites/default/files/assets/pdfs/pediatric_toolkit_for_health_care _providers.pdf

What else is behind your door?

Grades?
Uncertainty?



Anxiety: It's not all bad...



Emotional Context



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Correlates of Depressive and Anxiety Symptoms in Young Adults with Spina Bifida*

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- -High rates of depressive and anxiety symptoms in SB
- -The following variables relate to depression
 - -attitude toward SB
 - -satisfaction with family functioning
- -Self-reported pain is associated with anxiety symptoms

Music

- "Listening to my favorite bands sometimes takes my nausea and headaches away. Music is the best medicine."
- "My grand baby is 3 1/2 and she seems to get calm with music or playing on an iPad.
- "Music is the best. I played flute during childhood through college, took a long break, and came back to it when I realized I could once again carry a tune. I always feel better when I'm playing or listening to good music."

Music

- "My daughter listens to music and dances all day
- Music, playing on my tablet, or going for a walk is a stress reliever for me"
- "Wow! Our baby boy calms down and seems to be less stressed when he listens to his bear or train music play."
- "Good music and playing guitar help me out a lot."

Writing

- "Journals work for us."
- "Music definitely, writing, and dancing"

Prayer

- "Prayer and focusing on goals."
- "Music, prayer, and friend support!!!"

Take home message

- The experience of trauma and chronic stress impacts the person with hydrocephalus
- We need trauma-informed assessment and consultation in our medical care systems
 - At the time of the traumatic event
 - Immediately after the traumatic event
 - Longer term traumatic responses
- The stress and trauma of individual's medical condition extend to siblings, parents, and general family functioning
- Beliefs about medical condition are important
- How do you and your family manage the stress of Hydrocephalus?

Take home message

- Trauma-informed care / prevention (Coping session later today)
- Education
- Intervention when necessary
 - Trauma-based Cognitive Behavioral Therapy
- Coping Activities
- Sports
- Support communities

- Thanks to Amanda Garzon!
- Thanks to sitesolutions!
- Thanks to everyone who contributed on facebook and in person today!