

Communicating About Medically Unexplained Physical Symptoms (MUPS)

The Problem:

- Families of children with MUPS present frequently in the inpatient setting.
- They are often time intensive, demanding, and difficult to assess and treat.
- Families tend to be wary of psychiatric services and as a result are often difficult to engage.
- They are often upset with the medical team for failing to find an explanation for the symptoms.
- Families tend to deny any psychological or relationship issues within the family system.
- They report feeling misunderstood by the medical and CL team.

What are MUPS:

- MUPS is any clinical presentation where symptoms and impairment cannot be explained by a known organic pathology. The symptoms are present in the absence of medical evidence for an underlying cause.

- Explaining absence of findings as "normal" is not reassuring
 - Families want to know what is wrong, not what isn't
 - Families need an explanatory model for the likely cause of symptoms
 - Benign findings may satisfy physician level of certainty for ruling out a condition
 - Can increase family/patient anxiety for uncertain diagnosis and unknown prognosis
 - Conveying uncertainty (i.e., "we don't know what is causing you to ...") is not accurate and sends the wrong message to families. WE DO KNOW what is going on.

"The "normal" test results help us understand what is likely going on. We know that your _____ is not caused by something we can see from the clinical test. This means that there are a variety of other factors influencing your _____, such as diet, activity, stress, and the way your brain and body are communicating about your experience. Managing all of those factors is going to be our best way to treat your _____."

"Because we know that traditional testing is likely to be "normal" when a functional process is contributing to the symptoms, more testing is not likely to help us understand what is going on."

Explaining Treatments to Families:

- Physical symptoms always have a physical basis, but can be attributed to pathologic or functional processes

"If we suspect a pathologic process, we can often use certain clinical tests to detect the pathology, prescribe medication, surgery, or supportive treatments such as changes in routines, diet, skills to deal with stress, sleep, and physical activity."

If we suspect a functional process related to the disruption of normal physiologic function we use clinical examination and history as our "tests", and we most often prescribe changes in routine, diet, sleep, and physical activity as well as skills to deal with the stress of making these changes."

- Treatment needs to be multimodal and behaviorally/ functionally oriented

"Treatment, like cause needs to be multimodal and incorporate ways to manage a variety of possible triggers, which may include changing behaviors or habits, improving sleep and diet, changing structure of activity, relaxation techniques, management of potential stressors, and following up with your medical provider for regular examination)."

- Physical/ rehab arm: OT, PT, to address immobility and function; daily self-care plan to increase independence and success with daily care activities
- Medical arm: pharmacotherapy if necessary for pain, motility issues, muscle spasm, or comorbid anxiety or depression, as well as dietary issues
- Psychological arm: individual CBT therapy to teach mind-body strategies for managing pain and symptoms, as well as any comorbid anxiety/depression; Family work to enhance treatment and support parents in increasing independence at home
- Educational arm: return to school and if relevant school interventions to address educational or functional difficulties

- The purpose of all prescribed should be clarified

"Mental health interventions help prevent secondary problems that perpetuate symptoms such as anxiety, stress, and depression"

"Activities such as eating, sleeping, school attendance, and physical activity are best managed behaviorally"

"Complementary and alternative medicine therapies are useful for pain management"

- Take a "chronic treatable" perspective

"There is no acute problem with a cure that we can implement"

- Focus on functional improvement rather than symptom elimination

- Treatment goals will be reconditioning of the body and mind to work towards return to function in physical, emotional, academic, and interpersonal arenas
- For most kids symptoms completely resolve, *after* functioning has returned

Explaining MUPS to families

- Families need to know you understand their illness experience

“Tell me about your illness from the beginning.” “When was the last time you felt completely healthy?”
“What happened next?”

- Combine medical and psychosocial elements in your examination

“What hurts?” “Followed by” “What does the hurt stop you from doing?”

- MUPS is not simply a psychiatric illness
- It is clinically useless to make a cause and effect link between emotional distress and physical symptoms

- Families are often skeptical and defensive of psychiatric etiology
- Interpreting symptoms as a mental disorder in somatic form can raise doubts about the genuineness of the patient's suffering

- Anxiety, depression, and stress, are not a universal feature of MUPS
- MUPS can arise without concurrent depression or anxiety
- Psychiatric symptoms associated with MUPS may be the result of symptoms, rather than the cause

- Explain the relationship of the brain to the body in perpetuating symptom presentation
- Physiologic conditioning

- All symptoms are made up of a peripheral sensation and the cortical elaboration of that sensation. There is no consistent relationship between the amount of demonstrable disease and the subjective amount of distress perceived by the patient.
- Conditioned responses are patterns based on normal physiology that occur when a repeated stimulus causes a repeated response
- Can often identify a triggering event such as an infection, a stressor, and injury
- The result can be responses linking to other stimuli or occurring in the absence of the original stimulus
- These symptoms then can take on a life of their own
- Secondary gain can happen as a byproduct of dependence on caregivers, reduced demands on the patient, and reduced activity

- Psychosomatic pathway
- We have a baseline ability to perceive physical sensations (stomach, chest, head are most common)
- Early in childhood some individuals are more sensitive to these perceptions and often experience limb pain, belly pain, fatigue, insomnia, or neurologic symptoms
- Reinforcement over time can lead to greater somatic expression

- Multiple trigger and precipitants
 - Anything mediated through the central nervous system can realistically "cause" the symptoms to occur. (this can include fatigue, stress, habits, environment, anxiety or depression, sensory stimulation)
 - The body has a limited number of ways to respond to various triggers
 - Many things can trigger a single symptom or response
- Reflexes
 - Emphasis on automatic, involuntary, subcortical reflex actions at work
 - Body, Psychological, Social interactions
 - The body has structural (disease, damage) and functional (avoiding movement, sleep, and arousal) contributions to MUPS
 - Affect (emotions experienced) and behaviors (by child and family) are psychological contributors to MUPS
 - Social systems can unknowingly elicit certain signals and responses through social learning and reinforcement of responses. (Evidence suggests that pain and fatigue and sleep can be conditioned to certain environmental stimuli, resulting in avoidance.)

Sample Scripts:

"Because we know that traditional testing is likely to be "normal" when a functional process is contributing to the symptoms, more testing is not likely to help us understand what is going on."

"We could order that test. However, based on your history I suspect that the cause of your pain is a conditioned response in your body that will not show up on any test."

"Based on your history and physical examination I am confident that your headaches are related to muscle tension or spasm. The muscles on the side of your head are pretty tender and those attach to your jaw, resulting in pretty consistent pain. I know that you and your parents are worried you might have something more serious going on. We can get a CT scan to give you reassurance that nothing else is happening. Even before the CT scan comes back normal though, we can start working on some things to help reduce your pain and suffering and increase your ability to do things. For one thing, you aren't sleeping very well and we know that sleep problems are related to this kind of muscle tension. There are likely other things which can cause that muscle to contract involuntarily that we can resolve."

"There appear to be a lot of factors contributing to your {abdominal pain, diarrhea, IBS}. For example, bowel wall spasm causes the same problem whether it is related to IBS or to something else. It is also mediated through your central nervous system, so it can be made worse by things like stress, anxiety, or emotions. Because we think there are multiple factors contributing to your _____, there is no single thing that will provide full relief. It is more realistic for us to manage your symptoms by working on a variety of therapies, rather than searching for a single cure or treatment. This will likely include recommendations for how you manage your diet, psychological issues like anxiety or stress, your bowel habits, relaxation and pain management techniques, sleep, medication, and physical activity. If each of these accounts for even 10% of your symptoms, I believe we can improve a lot more than that by working on all of them."

"Your EEG was normal during the movements that looked like seizures. Therefore we know that the muscles were not twitching because of a seizure. But they were twitching when they weren't supposed to and you definitely did not want them to. Somewhere along the pathway between the nerves and the muscles, the message is firing incorrectly. This isn't anything permanent and should get better over time. But you don't have to just wait until your symptoms get better; there are some things that we can help you with to get those signals to work the way you want them to when you want them to."

"We can describe persistent pain in terms of structure (the presence or absence of disease or tissue damage) and function (things that the body does that influences pain such as reduced movement or physiological arousal). The pain you are experiencing is not associated with structure, so we can be confident that it is likely functional, or related to triggers that you can learn to control."

"You are having what is referred to as functional abdominal pain. Although we cannot locate a cause for your stomachaches and diarrhea on your medical tests, we understand that they are painful, and distressing and getting in the way of your life. We have learned that kids with stomach complaints often experience distress about other things too, such as not being able to find a bathroom or having stomach

problems away from home. That can be a problem because the discomfort in your body can make you feel even more distress which could make your stomach feel even worse. Behavioral health treatments can teach you ways to help your body feel better and also find better ways to manage your distress.”

“We know that in addition to tissue damage, pain can be evoked by a variety of factors, including thoughts, emotions, previous learning, suggestion, and the emotional states of others. When pain is present, these factors can all exacerbate the experience. The neural structures that are activated by pain are also involved in the processing of other states, such as disgust, anger, fear, and sadness.”