therounds

The broader context of pain: Bridging the gap between physical and mental health

SKIP AMA Highlights

Led by

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solutions for kids in pain
pour la douleur chez les enfants

Highlights

Report

Dr. Melanie Noel

Intergenerational Transmission of Chronic Pain

Emerging research is showing that 50% of parents of youth who have chronic pain, have chronic pain themselves. While there is clearly genetic transmission, we have started looking at the role of early life trauma as a risk factor for pain in the next generation.

A brand new paper showed that the rates of adverse childhood experiences (i.e., abuse, neglect, household dysfunction/challenges), especially physical neglect, are prevalent in parents of children with chronic pain. The next question is, how does early life trauma 'get under the skin' to confer risk to the next generation and can this be reversed?

- Intergenerational examination of pain and posttraumatic stress disorder symptoms among youth with chronic pain and their parents
- Adverse childhood experiences in parents of youth with chronic pain: prevalence and comparison with a community-based sample

Comment by Dr. Lindsay Uman

Observations from clinical practice:

Many youth and families presenting to pain clinics/specialists report traumatic experiences related to experiences with health professionals. Often they have been told (explicitly or implicitly) that their pain is not real, exaggerated, or “in their head” (psychological), particularly if medical tests have come out “normal”. This is extremely invalidating and painful for youth and parents, with families often describing these experiences as “traumatic”. We have to remember that not all types of pain is visible on medical tests. As health professionals we also have to be aware that normal tests results may not always be seen as reassuring or “good news” for families. Often it leaves them with more questions, confusion about why they still have pain, and disappointment/hopelessness that they will ever get better. We need to be mindful and sensitive to how we ask about pain or deliver medical findings. Often a simple question like “what do you think about this” or validating statement like “sometimes hearing that results are normal can actually be pretty upsetting when you were hoping to find a reason to explain why you’re feeling this way”.

Highlights

Report

Dr. Lindsay Uman

How to screen for common mental health issues

It can be challenging to know if/how to assess for common mental health issues, especially when appointments are shorter or focused on other areas. However, by having other medical or health professionals at least screen or inquire about mental health, it continues to reduce stigma and gives the message that mental health is part of overall health. Our brains are part of our body so it's important to acknowledge this and to be careful not to create an unnecessary divide between physical and mental health. There is so much overlap between physical and emotional pain and often you don't have one without the other because it's all part of overall health and everything is connected. It can also be helpful to ask about recreational drug and alcohol use in a non-judgmental way, often when meeting with the youth alone in order to increase their comfort level as they may not feel comfortable answering these types of questions with a parent present.

The table below (see appendix) is by no means comprehensive but provides some ideas for why and how to screen various mental health areas. If any potential concerns arise, it is also important to encourage and support families in seeking out the necessary supports (e.g., through self-referral to a mental health clinic or professional) to further assess and/or treat these areas. If you have questions or suggestions for other ways to ask/screen about these issues, please feel to post your thoughts.

Comment by Dr. Melanie Noel

There are also valid and reliable questionnaires that can be used to assess many of these mental health issues! High scores on these measures have been shown to be very important in predicting children's pain outcomes over time. It is also critically important when treating pediatric chronic pain to also consider parents' own mental health as these are some of the most powerful predictors of child pain outcomes. The measures we like to use, many of which have established clinical cut-offs (to indicate when symptoms are "clinically elevated" and need to be treated) are:

Child Anxiety and Depression: Revised Children's Anxiety and Depression Scale (RCADS)

Parent Anxiety and Depression: Hospital Anxiety and Depression Scale (HADS)

Child PTSD: Child PTSD Symptom Scale (CPSS-5)

Parent PTSD: PTSD Checklist for DSM-5 (PCL-5)

Sleep disorders: Insomnia Severity Index (ISI)

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Report

Dr. Melanie Noel

Diagnostic Uncertainty

One of the biggest "elephants in the room" in pediatric chronic pain is diagnostic uncertainty, which is the belief that an explanation or diagnosis for one's health problem is inaccurate. We find that over a third of children with chronic pain and their parents, who are seen in tertiary level chronic pain programs, believe that something more sinister/serious is going on with their child's pain that the doctors have not yet found. This uncertainty hurts: It is linked to worse pain and emotional functioning. And we find that central to this experience is a lack of trust in the medical system and in families' experiences with medical providers. We also find that clinicians themselves experience uncertainty in treating youth with chronic pain. They report sometimes being uncertain about when to 'draw a line in the sand' to stop diagnostic tests in the quest for a "cause" for the child's pain. While some clinicians think these investigations and diagnostic testing are helpful for families, families tell us this can lead to even more anxiety.

- Diagnostic Uncertainty in Youth With Chronic Pain and Their Parents
- Physician diagnostic uncertainty in pediatric chronic pain

Comment by Dr. Lindsay Uman

One of the biggest struggles reported by families presenting to Complex/Chronic Pain specialists is that they find it very upsetting/unsettling that nobody has been able to find the cause of their pain. With certain pain conditions like neuropathic pain, often there is not an identifiable injury or disease that has been found. If a family feels like something has been missed, this can be very unsettling and create distrust. This is why pain education is so important. It's important for families to understand how it's possible to experience real pain in the absence of injury/disease and that the necessary medical tests have been performed (where relevant). If youth or parent(s) believe they're in an underlying medical diagnosis/issue that has been missed, this belief can impact treatment success with them believing that until a "cause" is found, they will never improve. Again, it's important to validate, educate, and listen to the concerns/ questions of families. Beliefs and perceptions affect not just our emotional responses, but also our physical ones as well, including our bodies' pain signals. To read a short summary of two key case examples to demonstrate this, please see this brief article explaining the "Tale of Two Nails".

Highlights

Report

Dr. Lindsay Uman

Trauma and sleep disturbances: Observations from clinical practice

Sleep disturbances are common, especially in youth with chronic pain. Sleep hygiene (i.e., strategies to help address problematic sleep habits) can be helpful; however, often youth need more assistance with how to implement these strategies in realistic ways. For example, most youth and parents are aware that screen time before or in bed can negatively impact sleep. However, they may struggle with how to realistically reduce screen time, especially since it often meets various needs (e.g., distraction, social connection).

Sometimes a gradual (rather than 'all-or-nothing') approach can lead to more meaningful changes. This may involve supporting youth to gradually turn off their screens 10 minutes earlier each night, moving from watching screens to listening only, and trying to gradually decrease the duration or frequency of naps. Assessing patient motivation or readiness to make these changes now can also be helpful. A simple way to do this is use a traffic light analogy to assess readiness or motivation to work on this area now (red= not at all, yellow= somewhat, green= completely). Another way to assess readiness or motivation can be to use number scales (e.g., 0= not at all, 10= extremely). For example, you might say something like: "It seems like you're having a lot of challenges with sleep. There are various strategies that can help with this, but they do require effort and willingness to try them. How important is it for you to improve your sleep now (0 to 10). How confident are you that you can work on (insert small step) this now (0 to 10). Providing information alone often isn't enough to result in lasting changes. Often, engaging the help of a health professional trained in sleep strategies (e.g., psychologist) can be very helpful, particularly for youth/families who have been struggling with disturbed sleep for some time.

Comment by Dr. Melanie Noel

A few years ago, we found that children with chronic pain (and their parents) have much higher rates of PTSD than youth without chronic pain (and their parents). Kids who come to our pain clinic with high PTSD symptoms tend to see a worsening of their pain over time. Importantly, we find this happens because their sleep is disrupted. This means that if we can identify kids who have high PTSD symptoms and help them improve their sleep, we might be able to help them get better sooner.

- Posttraumatic stress disorder symptoms in youth with vs without chronic pain

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Dr. Melanie Noel

Parental Mental Health

Most of our treatments focus on helping children with chronic pain think differently about their pain and get back to activities (school, social activities, etc). Some treatments help parents change their behavior to be less overprotective to help their children engage in activities. What's missing is addressing parents' own mental health.

We know that parenting a child with chronic pain can take a toll on parents and lead to depression, anxiety and PTSD. This is critically important for children. We have found that parents' own mental health is one of the most powerful predictors of children's pain outcomes and others have shown that it is linked to children being less responsive to pain treatments. We think treatments need to advance to actually help parents with their own mental health issues. Exciting research is beginning to do just that and we think this will be transformative in pediatric chronic pain care.

- The (Parental) Whole Is Greater Than the Sum of Its Parts: A Multifactorial Model of Parent Factors in Pediatric Chronic Pain
- Longitudinal change in parent and child functioning after internet-delivered cognitive-behavioral therapy for chronic pain

Comment by Dr. Lindsay Uman

Observations from clinical practice:

It can often be tricky to figure out how to assess the impact of parental mental health on a child, particularly when the focus of most pediatric appointments in on the youth. However, mental health disorders often run in families so parental mental health is directly relevant. For example, parents with unmanaged anxiety or depression may intentionally or unintentionally pass their beliefs to their children. We often see this in various ways including:

- Youth interested in trying medication(s) for pain but parent(s) reluctant due to their own negative experiences or worries (e.g., about addiction)
- Parents with their own mental health disorders or ADHD may end up forgetting about their child’s medical appointments or forgetting what was recommended.

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Appendix

Table, Slide 3 (How to screen for common mental health issues)

Mental Health Issue	How it can impact pain and/or pain treatment	Some ways to screen or ask about this
Anxiety	Stress increases pain and tension & vice versa; Anxiety can have physical symptoms (e.g., stomachaches, nausea).	Do you notice your pain gets worse when you are stressed? When you are in pain, does it increase your stress/anxiety? Rate anxiety from 0 to 10 (0= none, 10= most).
Depression	Depression can lead to hopelessness, poor sleep, poor memory, lack of motivation, and self-harm/ suicidal thoughts/plans/actions. Some pain medications can increase suicidal thoughts.	Do you have times when your mood is really low? Have you ever thought about or tried to hurt yourself on purpose (self-harm)? Do you have every have thoughts about wanting to die or killing yourself? Rate mood from 0 to 10 (0= lowest, 10= best).
Eating Disorder (or Disordered Eating)	Food restriction, binging, purging, and/or excessive exercise can have severe physical consequences; Purging can affect medication absorption; Youth may resist taking medications (especially if weight gain could be a side effect).	Do you ever try to limit your food intake in order to lose/gain weight? Do you ever do other things to lose/gain weight (e.g., purging, fasting, excessive exercising)? Do you have any body image concerns?
Obsessive Compulsive Disorder (OCD)	Obsessions and compulsions can be related to pain or health issues. People with OCD can get stuck in a pattern of rumination that can be hard to break without treatment.	Do you experience intrusive/disturbing thoughts (obsessions) that you can't get out of your head no matter how hard you try? Do you feel you need to perform certain rituals or behaviors (compulsions) to help make these thoughts go away?
Attention Deficit Hyperactivity Disorder (ADHD)	Limited attention and focus can make it hard for youth or parents to retain or remember information. Medication doses (especially medications prescribed as bid or tid) can be forgotten. Repetition and providing information verbally and in writing can help.	What do you see as the main take-home messages or next steps from this appointment? What will help you remember to… (e.g., take your medication)? Would setting reminders on your phone help?
Trauma or PTSD	Trauma can cause a multitude of physical symptoms that can impact pain (e.g., poor sleep, avoidance, tension).	Are there any current or past events/situations you've experienced or witnessed that have had a strong negative impact on your life (e.g., bullying, abuse, divorce, death of a loved one, violence)?
Sleep disorder(s)	Poor sleep can increase pain, and pain can increase sleep disturbances. Lack of sleep is associated with a host of other health issues. Youth (especially adolescents and those with chronic pain) often report getting much less sleep than recommended. Medications can often have side-effects that affect sleep (e.g., can increase fatigue).	How is your sleep? Do you have trouble sleeping due to you pain? What time do you typically got to bed, fall asleep, and wake up? Do you wake up during the night (if so, is it because of pain? Do you take naps (if so, how often and how long)?
Recreational drug or alcohol use.	Many youth will self-medicate their pain (physical and emotional pain) through recreational drug or alcohol use, which can lead to dependence and other concerns. Many youth will be hesitant to admit this to parents or health professionals for fear of being judged or getting in trouble. Other drugs and alcohol can interact with prescribed medications.	I want to ask you some questions about drug and alcohol use because these things can impact overall health and can interact with other medications. I'm not going to judge your response, so I want to encourage you to feel comfortable being completely honest. Do you use alcohol or recreational drugs (e.g., marijuana)? If so, how often and how much? What do these drugs do for you?