The Roadmap Initiative: Improving Support for the Emotional Health and Resilience of Children with Chronic Conditions and Their Families

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Why did you choose this session?

• What do you hope to learn?
Background: the Roadmap Initiative
Partnering with Patients and Families to Advance Quality
September 2016
65% of pediatricians, including subspecialists, surveyed by the American Academy of Pediatrics indicated that they lacked training in recognizing and treating mental health problems.
Current child health systems have responded vigorously to the physical health challenges of chronic childhood disease but less consistently to the challenges of proactively supporting the wellness of patients and families.
Roadmap’s Goal

Increase the resilience and emotional health of children with chronic conditions and their families by:

• Raising awareness among patients and families to ‘validate’ stress and promote self-care

• Raising awareness among clinical teams to address these issues and provide support

• Providing resources and connections for clinicians and families

“Many times, we don’t want to appear to need emotional help because we don’t want to appear to be unable to care for our child...we want to seem to have our act together even though we may only be holding on by a thread.”
This **brief video** highlights the power of **four simple words**.
Reflections
Addressing emotional health needs of patients and families with chronic conditions is important, evidence-based and feasible.
Nearly twice as many youth with CMCs had mental health diagnoses compared to healthy youth.

Similar rates of substance use diagnoses in youth with CMCs compared to healthy youth.
Importance

• ...that’s only among those with **documented** mental health and substance use diagnoses.

• Youth and young adults with chronic medical conditions (ages 0-26) and co-occurring mental health or substance use disorders had annual insurance payments **2.4 times larger** than those with a chronic medical conditions only (Perrin et al., 2019)
Evidence-base

• Adherence and self-management
  – Nonadherence is related to increased health care utilization and poorer health outcomes across youth with CMCs
  – Effective interdisciplinary adherence promotion interventions improve patient QoL and family-level outcomes and decrease healthcare utilization (McGrady & Hommel, 2013)

• Mind-body connection
  – Symptoms of anxiety and depression are associated with increased patient-reported symptoms and poorer health outcomes across several pediatric CMCs (e.g., IBD, type 1 diabetes, asthma, cystic fibrosis)
Feasibility

• Psychosocial screening standards in specialty clinics and disease-specific resources
  – Type 1 diabetes, inflammatory bowel disease, cystic fibrosis, oncology

• Pediatric patient-centered medical homes (Kazak et al., 2017)
  – Leads to improved health outcomes, enhanced patient and provider experiences, and reduced costs associated with unnecessary hospital and ED visits
What we have learned

• You don’t have to be a mental health professional to make a difference.
• Begin the conversation early
  – Support regular self-care: sleep, exercise, unplug, mindfulness
• Use ongoing surveillance as well as screening at specific ages to identify and help those at risk.
• Develop a list of resources/referrals (and gaps)
Resources
https://www.abp.org/foundation/roadmap
We’ve developed resources you can use...

**Background and Aim**

Living with a chronic pediatric condition is challenging, and can cause stress, altered coping, and lasting impacts on child and family emotional health. Emotional health support often lags physical care. The prevalence of behavioral and mental health conditions in children, adolescents and young adults is significant.

The Roadmap Project aims to increase the resilience and emotional health of pediatric patients with chronic conditions and their families by:
- Raising awareness:
  - among patients and families to ‘normalize’ or validate stress and promote self-care,
  - among clinical teams to address these issues and provide support, and
- Providing resources and connections for clinicians and families.

**Coming Soon**

- Maintenance of Certification (MOC) Part II module with background of topic, overview of Roadmap key points, and post-review self-assessment
- MOC Part IV with suggested metrics that could be used in run charts to track change over time.
- Curriculum outline and template(s) with associated slide deck for use in teaching sessions.
- Development of suggested staging to aid in implementation.

Funded by the American Board of Pediatrics Foundation, the Roadmap Project aims to increase the resilience and emotional and mental health of pediatric patients with chronic conditions and their families. Direct questions to the Roadmap Project Team: abp_fdm_project@cbcorp.org
Change Package

Concrete, useful tools & strategies
“Drivers” to support resilience and emotional health

1. Patient/family and clinician awareness
2. Care team clinician knowledge, know-how, and confidence
3. Patient/family resilience fostered
4. Peer-to-peer support
5. Surveillance/assessment/screening is built into visit and family workflows
6. Resources are available and accessible
### Potential Changes to Test

**DRIVER 1:** Patient/family and clinician awareness of: the impact of a chronic pediatric condition on mental and emotional wellbeing; the need for improved emotional and mental health support including surveillance, screening, treatment, and follow-up; and the potential mitigating role of resilience.

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<th>Rationale</th>
<th>Potential Resources and Example Changes To Test</th>
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<td>“You can’t get clinician and staff buy-in if they don’t understand the impact of a diagnosis on the individuals and families they treat.”</td>
<td>University of Michigan Medicine provides <a href="https://www.med.umich.edu/">online information</a> for parents about how children cope with chronic conditions, how families may be affected, ways the family and child can better cope.</td>
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<td>Patients and families:</td>
<td><strong>6 Steps</strong> to Help Move Through a Serious Diagnosis for Your Child.</td>
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<td>• Need heightened awareness of the very normal emotional and mental health impacts of the conditions with which they are living</td>
<td>The Interactive Autism Network article <a href="https://www.autism.org/">Stress and the Autism Parent</a> aims to 'normalize' the feelings of stress parents of a child with autism may face, and provides practical tips for addressing it.</td>
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<td>• May have limited awareness of the potential major impact of physical health on mental and emotional wellbeing</td>
<td><strong>Autism Speaks</strong> provides <a href="https://www.autismspeaks.org/">Family Support Tool Kit</a> (for parents, siblings, grandparents and friends) to help teach more about autism and its effects on families.</td>
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<td>• Should be able to expect that they will receive emotional and mental health assessment and follow-up from their care team.</td>
<td>The <a href="https://www.cff.org/">Emotional Wellness</a> section of the Cystic Fibrosis Foundation website provides information and blog posts about anxiety, depression and coping for CF patients and caregivers.</td>
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| Clinical teams must cover a range of issues including, often, pressing concerns related to physical health. Their clinical training emphasizes the physical aspects of illness, so exposure to emotional and mental health issues is likely lacking. | Sisters by Heart and NPC-QIC co-produced [parent brochures](https://www.sistersbyheart.org/) to address feelings, coping and support at various stages of chronic illness.
Framework

- **Be Aware**: Become aware of the potential for emotional and mental health challenges, the role of resilience.
- **Educate**: Educate clinicians and families on available tools and resources.
- **Mitigate**: Promote strategies to support resilience and mitigate emotional health challenges.
- **Surveillance and Screen**: Check in with families; conduct ongoing surveillance and use screening at regular intervals.
- **Intervene**: Provide empathy, intervention and resources for those identified at risk or struggling.
- **Follow-up**: Provide follow-up after referrals.
Example Conversations
“I haven’t really asked patients or families about emotional health. How do I start?”

“Our center is going to start annual anxiety and depression screening for teens. How should we explain this to patients and families?”
Each conversation includes
- Components of the conversation
- A sample “script”
- Considerations and reminders

Developed in consultation with patients, parents, and health professionals

Not condition-specific and are suitable for a variety of chronic conditions
Slide set introducing the Example Conversations

Who Needs Example Conversations?

- Communicating about resilience and emotional health with patients and families is important... but not always easy!
- Health professionals often feel ill-prepared to have these discussions and are not sure what to say.
- Understanding the key components of common conversations and having “the words” can help.

Young Teen, Newly Diagnosed Chronic Condition

- Important components and considerations
  - Respect the patient’s voice, perspectives, and feelings as independent from the parent(s)
  - Be mindful of the teen’s developmental age/stage
  - Seek teen/family input on the amount of educational/anticipatory guidance desired
  - Incorporate individual/family strengths to promote resilience
- Download the Example Conversation [here](#)
Getting started and staging

• Identify your “team”
• Provide background to understand importance of emotional health of patients with chronic conditions and their families
• Identify resources and potential referral sources
• Build confidence and capability of clinical team
• Integrate surveillance & screening into clinic flow
Putting Roadmap resources to use in your setting

Practice with the Example Conversations
Example Conversations...

• With a parent/caregiver of a young child with a newly diagnosed chronic condition
• With a young teen and a parent/caregiver about a newly diagnosed chronic condition
• At a routine surveillance visit with an established patient/family
• Introducing depression screening for young teens with a chronic condition
Using the Example Conversations Discussion
Putting Roadmap resources to use in your setting
We’ve developed resources you can use... and we’re not done!
Getting started and staging

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Discussion
Questions?

Thank you!