



Roadmap College

Webinar #3

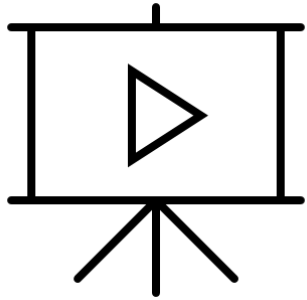
Develop Knowledge, Know-How, and Confidence, part 1

Thursday, July 14th

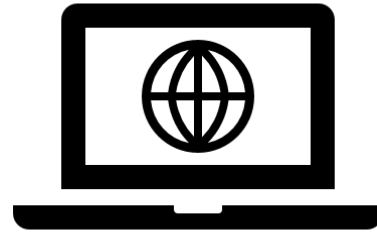
3pm - 4pm ET

Welcome & Current State

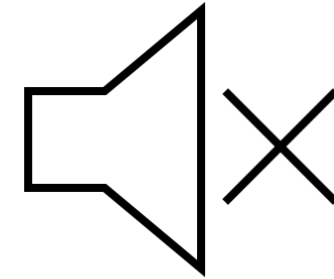
Abby Zier Alyesh



Webinar is
being recorded



Recording &
slides will be
posted



Mute mic

Housekeeping





Our goal,
simply put

*“Ask how the child
and family are doing.
Every visit. Every
time.”*



SETUP

STEP 1

Self-assess your readiness using the Readiness Checklist

STEP 2

Collect simple baseline data:

Was there documentation that patient and family emotional health was assessed during this visit?

STEP 3

Set an aim



TRY CHANGES, MEASURE IMPROVEMENT

STEP 4

Conduct PDSA cycles. Begin with Key Driver 1 and progress through Key Drivers 2, 3, and 4, focusing your tests of change on improvements related to your readiness self-assessment. Use the “potential change strategies” in the driver diagram to gather ideas to try. Start small; for example, one patient, one clinic day, one inpatient rounds. Revise as you learn and improve.

Key Driver #1: Develop Awareness

Use the potential change strategies to increase your awareness of the challenges and stresses of living with/parenting a child with a chronic condition.



Key Driver #2: Identify resources; make them available

Use the *Developing a Resource List* tool to create or update a list of resources specific to your practice’s location and patient population. Ensure you have a crisis plan for mental health emergencies for patients and for families.



Key Driver #3: Develop knowledge, know-how and confidence

Review Roadmap videos and conversation guides to develop or hone your approach to initiating conversations about emotional health.



Key Driver #4: Build assessment and surveillance into your clinic flow

Begin assessing emotional health at the time of diagnosis and continue through each clinical encounter.

STEP 5

Continue to test and measure ways to embed discussions about emotional health into your daily care. Collect additional measure data and repeat the Roadmap Readiness Checklist. Expand your successful PDSA cycles, and **implement successful changes**. Ensure that your measure data support the effectiveness of the changes as you move to implementation.

Objectives

Understand

Understand how to initiate discussions about emotional health with patients and their families.

Familiarize

Be familiar with the normalize-ask-pause-connect technique for initiating emotional health discussions.

Understand

Understand ways to make connections to appropriate support for patients and families who identify emotional health needs.

Agenda

5 min	Welcome & Current State	Abby Zier Alyesh
10 min	Resource List Recap	Carole Lannon Abby Zier Alyesh
5 min	Overview of Developing Knowledge, Know-how, and Confidence	Carole Lannon
35 min	Starting Discussions and Supporting Next Steps <ul style="list-style-type: none">• <i>Learn the Normalize, Ask, Pause, Connect technique for starting discussions about emotional health</i>• <i>Q&A</i>• <i>How to discuss therapy with patients and families</i>• <i>Q&A</i>• <i>Discussion</i>	Erica Sood Melissa Cousino
5 min	Next Steps	Abby Zier Alyesh

Resource List Recap

Carole Lannon



Power of peer support

“People gravitate toward peer support because of its *humanizing effect on our challenging health care system*. And we love that it provides that personal connection to better understand physical and emotional impacts of chronic illness and it is 100% patient-centered . . . peer-to-peer supports looks different for everyone, but that feeling of validation and understanding by someone who has walked in your shoes -- *we learn from each other and gain tools to live healthier lives as parents, patients, and siblings.*”

- Stacey Lihn



Jill's five steps to take to get started developing a resource guide

1

Ask around for existing resources - you may not need to reinvent the wheel!

2

Organize your resource guide by audience

3

Include patient/parent partners in developing materials

4

Consider how you can keep your list updated

5

Test it out! And ask patients/and families if they were successful in using the resource



Where we left off

- Establish or update your practice setting's list of resources to support the emotional health of children with chronic conditions and their families that includes:
 - local or national peer-to-peer support resources for patients
 - local or national peer-to-peer support resources for families (e.g., parents and/or siblings)
 - mental health providers (e.g., social workers, psychologists, psychiatrists, other licensed providers) in the health system and/or community, when available

988

SUICIDE
& CRISIS
LIFELINE



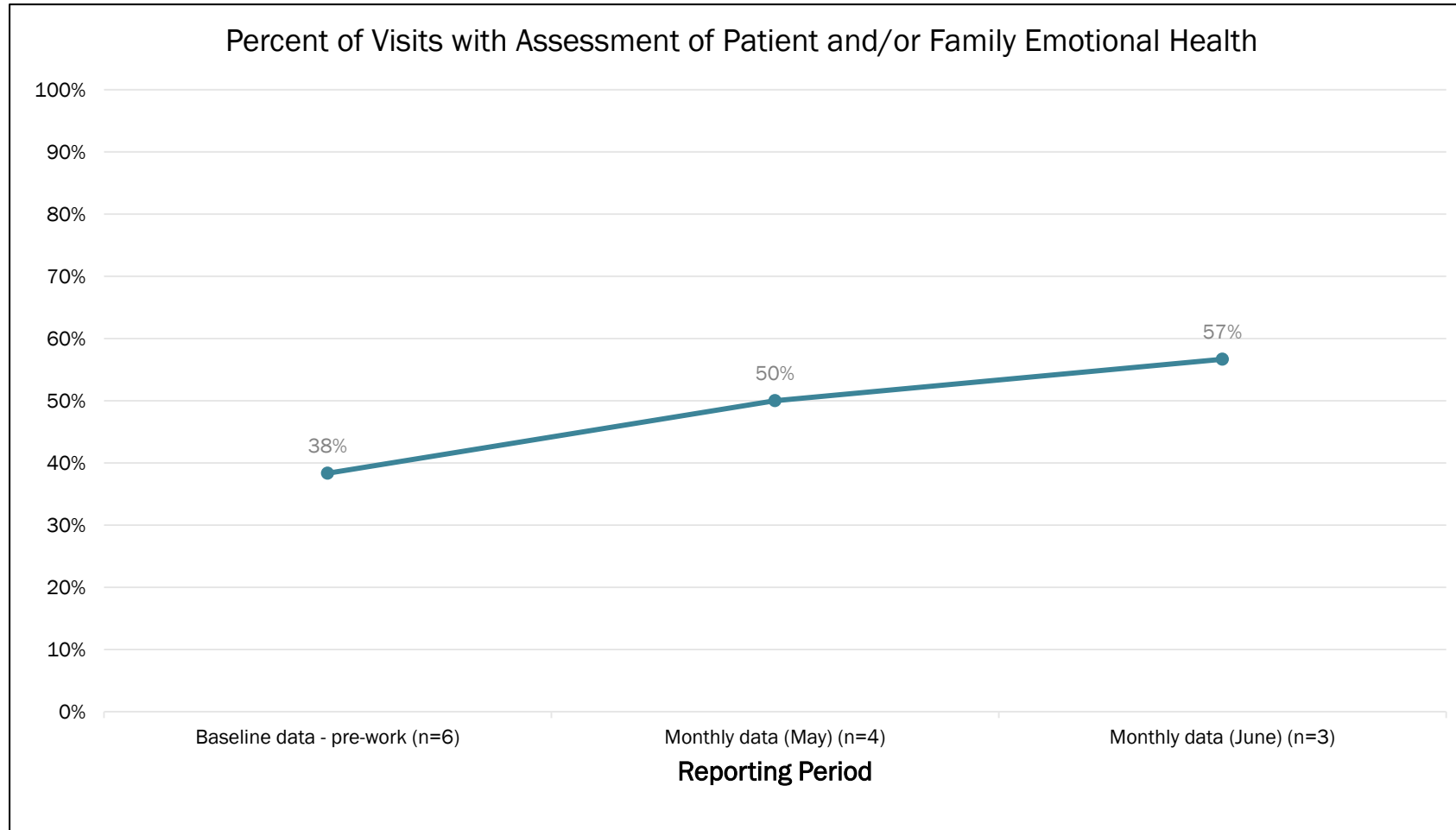
988 Live Saturday, July 16

In 2020, Congress designated the new 988 dialing code to operate through the existing National Suicide Prevention Lifeline.



June reporting

June range: 10%-90%



N=# of sites
Three sites reviewed
~10 charts each



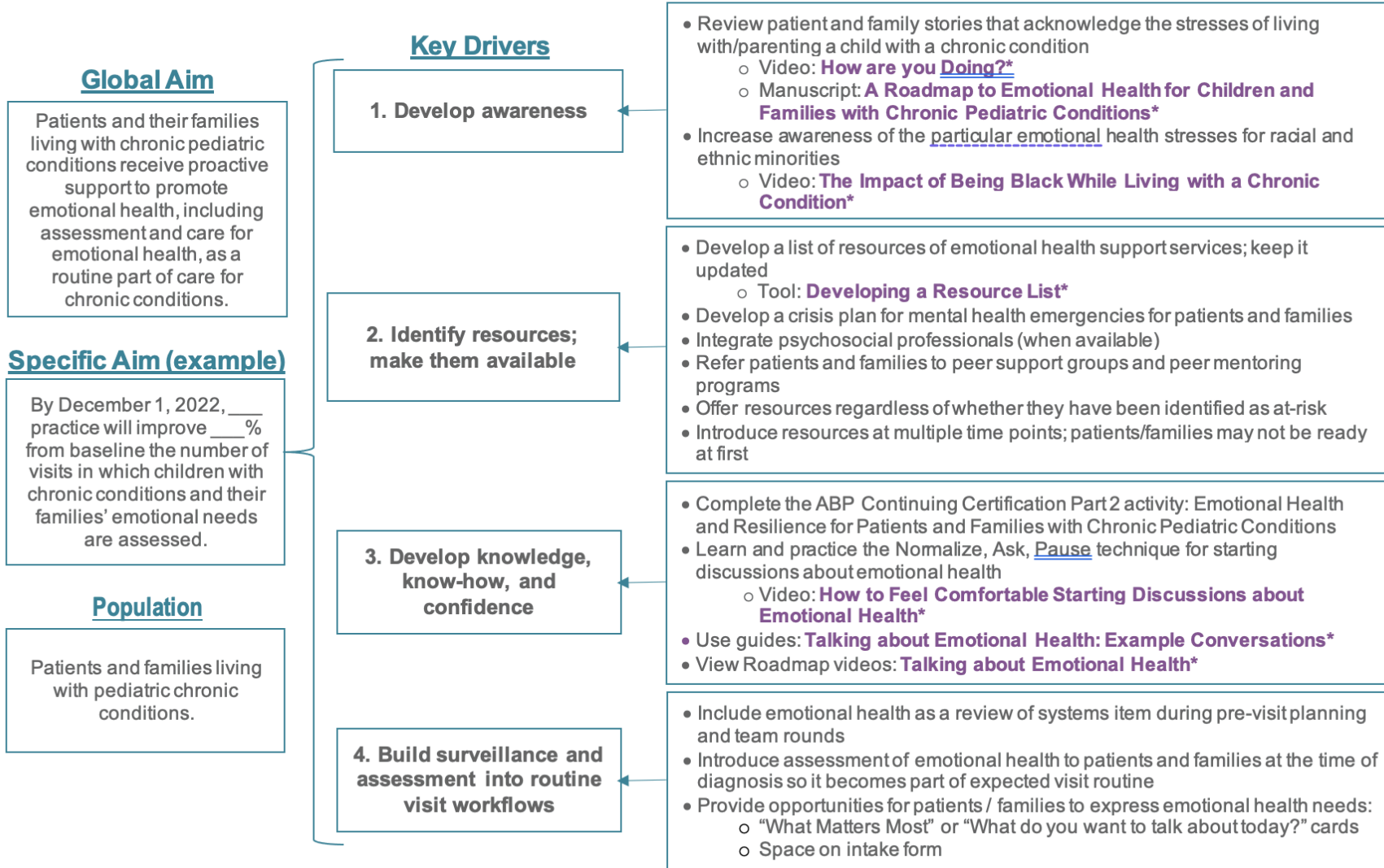
Discussion

- Small wins?
- Breakthroughs?
- Challenges?

Overview: Developing Knowledge, Know- how, and Confidence

Supporting Emotional Health for Children and Adolescents with Chronic Conditions and Their Families

Potential Change Strategies



*These resources are available on [The Roadmap Project's website](#)

Specific Aim (example)

By December 1, 2022, ___ practice will improve ___% from baseline the number of visits in which children with chronic conditions and their families' emotional needs are assessed.

Key Drivers

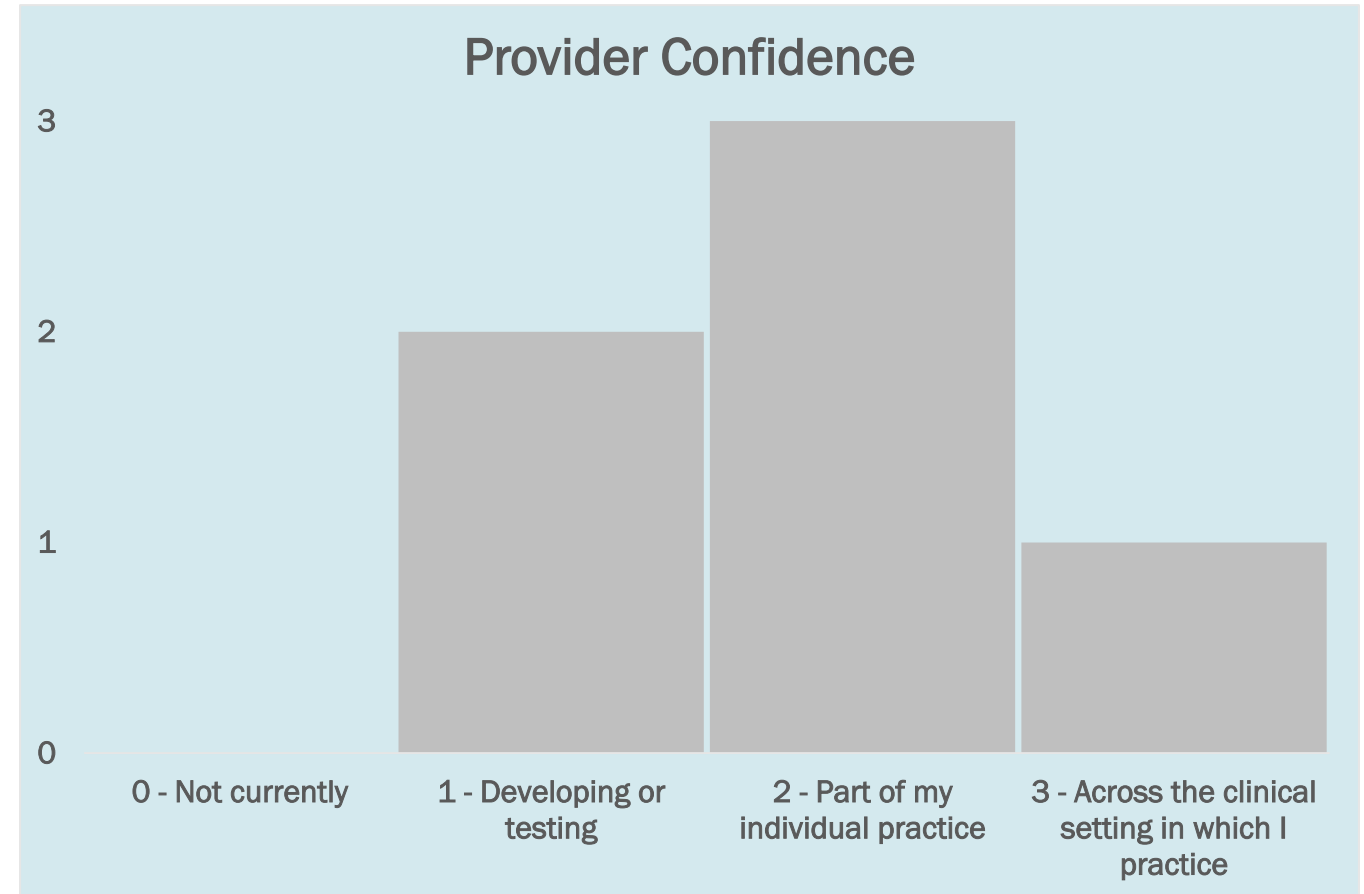
3. Develop knowledge, know-how, and confidence

Potential Change Strategies

- Complete the ABP Continuing Certification Part 2 activity: Emotional Health and Resilience for Patients and Families with Chronic Pediatric Conditions
- Learn and practice the Normalize, Ask, Pause technique for starting discussions about emotional health
 - Video: **How to Feel Comfortable Starting Discussions about Emotional Health***
- Use guides: **Talking about Emotional Health: Example Conversations***
- View Roadmap videos: **Talking about Emotional Health***

Self-Assessed Readiness (April 2022)

E. Providers in our practice setting feel confident and competent initiating discussions about emotional health topics with children, adolescents, and family members of children and adolescents with chronic medical conditions



Starting Discussions & Supporting Next Steps

Erica Sood
Melissa Cousino



Parent of a child with a chronic condition

“I think mental health, it should be proactive versus reactive... It doesn't need to be, ‘oh, I see a problem’... You have to be proactive with it... **we weren't offered any kind of psychological assistance until we had to be evaluated for transplant. Now, my daughter had already been through six open-heart surgeries at that point.** We had already spent almost a cumulative year in the hospital at that point, right? We had already gone down to one income. We had already been isolated from family and friends. We had already gone through so much to get to that point... But still, that was about, ‘Are you a candidate for her to get the heart?’ It's not, **‘How are you?’**”

Learn the
“Normalize, Ask, Pause,
Connect” Technique for Starting
Discussions about Emotional
Health
Erica Sood



Erica Sood, PhD

- Pediatric psychologist in the Nemours Cardiac Center and Center for Healthcare Delivery Science at Nemours Children's Health
- Associate Professor of Pediatrics at Thomas Jefferson University
- Directs the Nemours Cardiac Learning and Early Development (LEAD) Program



Normalize-Ask-Pause- Connect



Start the Conversation

NORMALIZE + ASK + PAUSE + CONNECT





Start the Conversation

NORMALIZE + ASK + PAUSE + CONNECT

- ✓ Communicate that emotional difficulties are common and expected in this situation
- ✓ Set up the discussion so that the easy answer is to acknowledge emotional difficulties
- ✓ Minimize the likelihood of “I’m fine”

Start the Conversation: Normalize

- “I know from working with other adults that it’s really common to feel down or depressed when [illness-specific stressor]”
- “Many people tell me that [illness] makes everyone in the family feel more anxious”
- “I hear from a lot of patients that they’ve had to grieve the loss of [pre-illness experiences]
- “I always ask about [emotions] because how you are doing emotionally is just as important as how you are doing physically



Start the Conversation

NORMALIZE + **ASK** + PAUSE +
CONNECT

- ✓ Open-ended
- ✓ Avoid checklist-like questions
- ✓ Less is more
- ✓ Pay attention to your non-verbal communication



Start the Conversation: Ask

- “How about you?”
- “How have you been affected?”
- “What has [illness-specific stressor] been like for you?”
- “How are you doing?”
- “How are you feeling?”
- “How has [illness] impacted you/how you feel?”



Start the Conversation

NORMALIZE + ASK + **PAUSE** + CONNECT

- ✓ Communicates that you want to hear the answer
- ✓ Gives the patient time to gather their thoughts and decide whether to share
- ✓ This may be the first time they've been asked
- ✓ Try again next time even if they don't share



Start the Conversation

NORMALIZE + ASK + PAUSE + **CONNECT**

- ✓ Use reflection and supportive statements to communicate that their feelings are normal and okay
- ✓ Inquire about existing supports and encourage use of these supports, including peer-to-peer support
- ✓ Connect patient/family with professionals who can offer additional resources



Start the Conversation: Connect

- “Thank you for sharing...It sounds like this has been a really hard time”
- “It makes sense that you feel this way”
- “Who have you been able to talk to about these feelings?”
- “Have you talked with other people who have been through this?”
- “We have a social worker who meets with many of our patients to discuss supports that may be helpful. Would you be open to meeting with him/her?”



Common Concerns: I will open Pandora's Box

- Use reflection, focus conversation on available supports
 - It sounds like things have been really tough. What has been helpful in getting through this, if anything?
 - I'm so sorry to hear that things have been so difficult. I really appreciate you sharing this with me. We have a social worker/psychologist/other MHP who meets with many of our families to talk about supports that may be helpful. Would you be open to meeting with him/her?



Common Concerns: I don't have the answers/resources

- Asking/listening is an intervention in itself!
- Consider who may have information about resources and offer to make this connection



Common Concerns: I don't know how to respond

- Reflect and normalize (try not to cheer up or talk about “strength”)
- Communicate that it is okay to talk about this, it is okay to show emotion, don't have to be “strong”
- Thank them for sharing
- Ask about available supports
- Connect them with someone who has information about resources, if available



Common Concerns: It'll feel awkward

- How do you ask friends/family how they are doing?
- Don't overthink it
- Start early in relationship
- Describe this as a practice change

Questions



How to Discuss Therapy with Patients & Families

Melissa Cousino



Melissa Cousino, PhD

- Associate Professor, Pediatrics and Cardiac Surgery
- Director, M-COPE, Psychosocial Services, UM Congenital Heart Center





Game
CHANGER



The
Roadmap
Project

THE AMERICAN BOARD *of* PEDIATRICS
FOUNDATION



1. The Validation

- We ask about your mental health because we expect young people with heart disease to sometimes experience XXX.
- Many tell me they feel sad (worried, angry, etc.) sometimes... sad about their heart or about friends or about other things.
- It can be hard to take medicines and do all the things we ask sometimes. Even I would have a hard time with...
- I know a lot of other kids/teens with heart disease who have found therapy to be really helpful.



2. The Why

- Mental health is SO important to your heart health.
- We know from research that sad mood or lots of worry can actually impact heart health – like blood pressure and inflammation.
- When we take care of our mental health, we are more likely to do things that are good for our heart, like exercise more and sleep better.



Table 1. Effect Estimates for Associations of Negative Psychological Factors With Cardiovascular Events and Conditions

Negative psychological factors	Parameter/end point	Effect estimates (95% CI)
Depression	Incident MI	RR, 1.30 (1.22–1.40) ⁴²
	Incident CHD	RR, 1.30 (1.18–1.44) ⁴²
	Stroke	RR, 1.45 (1.31–1.61) ⁴⁵
	Obesity	RR, 1.37 (1.17–1.48) ⁴⁹
	Hypertension	RR, 1.42 (1.09–1.86) ⁵¹
	Diabetes	RR, 1.32 (1.18–1.47) ⁵²
Anxiety	CVD mortality	RR, 1.41 (1.13–1.76) ³⁹
	Incident CHD	RR, 1.41 (1.23–1.61) ³⁹
	Coronary artery spasm	RR, 5.20 (4.72–5.40) ⁴⁰
	Incident stroke	RR, 1.71 (1.18–2.50) ³⁹
	Heart failure	RR, 1.35 (1.11–1.64) ³⁹
Work-related stress	Incident CVD events	RR, 1.4 (1.2–1.8) ¹⁸
Any-cause stress	Incident CHD/CHD mortality	RR, 1.27 (1.12–1.45) ¹⁹
PTSD	Incident CHD	RR, 1.61 (1.46–1.77) ²²
Social isolation and loneliness	Incident CVD events	RR, 1.5 (1.2–1.9) ¹⁸
Pessimism	CHD mortality	OR, 2.17 (1.21–3.89) ⁵⁰ (highest vs lowest quartile)
Anger and hostility	Incident CHD	HR, 1.19 (1.05–1.35) ³³
	Recurrent CHD	HR, 1.24 (1.08–1.42) ³³

CHD indicates coronary heart disease; CVD, cardiovascular disease; HR, hazard ratio; MI, myocardial infarction; OR, odds ratio; PTSD, posttraumatic stress disorder; and RR, risk ratio.

Mental Health IS Heart Health

American Heart Association, 2021

Psychological Health, Well-Being, and the Mind-Heart-Body Connection

ANXIETY

CVD Mortality Risk = Increase by 40%

SOCIAL ISOLATION

CVD Adverse Events Risk = Increase by 50%

MENTAL HEALTH CONCERNS

Upwards of 65% of teens with medical non-adherence



3. The Heads Up

- Therapy or counseling is one way to improve your mental health.
- The Heads Up - Process:
 - Our social worker will give you a list of referrals...
 - Luckily, at UM, we have a team dedicated to this.... it is that important...
 - Use Names/Show Partnership and Familiarity
 - I will put in the referral and someone will check your insurance and call you in the next few weeks from the psychology office to schedule.
- The Heads Up – Challenges:
 - Waitlists, personality “fit”



SUPPORT AND CONNECTION

M-COPE

University of Michigan
Congenital Heart Center
Psychosocial and
Educational Program

Heart Center Supports

- Social Work (Inpatient/Outpatient)
- Pediatric/Cardiac Psychology
- Cardiac Neurodevelopment Program
- Child and Family Life
- Education Liaison
- Book Babies Program
- Fontan Wellness Program
- Heart to Heart Caregiver Meet-Ups

Peer Supports

- All CHD
 - Mended Little Hearts Support Chat
- Single Ventricle:
 - Sisters by Heart, Linked by Heart Peer Groups
 - Fontan Outcomes Network, SV Connection Chats
- Transplant:
 - Transplant Families Caregiver Groups
- All Pediatric Illness:
 - North Star Reach Groups, Camps and Events

Learn More

Visit our website
by QR code or at
www.mottchildren.org



CONGENITAL HEART CENTER

PATIENT & FAMILY SUPPORT SERVICES



M-COPE, the U-M Congenital Heart Center Psychosocial and Educational Program, leads clinical and research programs to address stressors impacting our heart patients and families. We believe that emotional wellbeing is critical to both heart and family health! Our M-COPE team includes social workers, psychologists, child life and educational specialists, and peer mentors who are ready to help with a variety of concerns and needs.

To learn more about our patient and family support services or to view the Events Calendar, snap a photo of the QR code or visit the C.S. Mott Children's Hospital Congenital Heart Center website.





4. The Follow Up

- I am so glad we talked about this today. Thank you for sharing with me.
- During our last visit we talked about starting therapy... how has that been going?

Questions



Discussion



Team Question

- “How [does] prenatal care/prognosis provided in prenatal period continue to affect parents' social emotional health following birth into the first several months of life during the interstage period?”

Next Steps

Abby Zier Alyesh



Before Webinar #4

Takeaway tests:

- Try at least one idea you heard on the webinar today
 - Normalize, ask, pause, connect, other...?
- Consider ways to share your learning across your clinical setting

Tasks:

- Visit the Roadmap College participant page to see pre-reading
- Report Month 3 data on REDCap by July 29 (**including your mid-point Readiness Checklist self-assessment**)



Readiness Checklist

CHECKLIST COMPONENT Baseline

a. I am aware of the stresses of living with / parenting a child with a chronic condition and the importance of addressing emotional health, in addition to physical health, for patients/families with chronic pediatric conditions

b. My practice setting has an up-to-date list of resources to support the emotional health of children with chronic conditions and their families that includes:

- mental health providers (e.g., social workers, psychologists, psychiatrists, other licensed providers) in the health system and/or community, when available
- local or national peer-to-peer support resources for patients
- local or national peer-to-peer support resources for families (e.g., parents and/or siblings)

c. My practice setting has a crisis plan in place to handle mental health emergencies, including suicidality, for patients (Check N/A if your patient population is too young to experience a mental health emergency, such as infants)

d. My practice setting has a crisis plan in place to handle mental health emergencies, including suicidality, for family members (e.g., parents)

e. I feel confident and competent initiating discussions about emotional health topics with children, adolescents, and family members of children and adolescents with chronic medical conditions



Webinar #4

- Dr. Adrienne Kovacs will speak on Webinar 4. What questions would you like to ask her?
 - Put it in the chat
 - Or in your monthly progress report



Evaluation

