



Roadmap College

Webinar #1

Develop an Awareness of Emotional Health Needs

Thursday, May 12

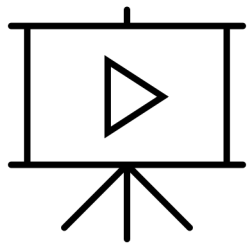
3pm - 4pm ET



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Welcome

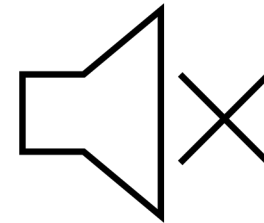
Abby Zier Alyesh



Webinar is
being recorded



Recording &
slides will be
posted



Mute mic

Housekeeping



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Objectives

Understand

Understand the current state of assessing emotional health of patients and families for whom you care.

Consider

Consider the ways emotional health affects your patients and their families.

Use

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



Agenda

5 min	Welcome & Introductions	Abby Zier Alyesh
10 min	Roadmap College Setup	Carole Lannon
15 min	Current State of Assessing Emotional Health for Patients and Families	Meg Didier Melissa Cousino
25 min	How to Develop an Awareness of Emotional Health Needs Among Clinical Teams <ul style="list-style-type: none">• Overview• Application and Q&A	Aliese Sarkissian Abby Zier Alyesh Carole Lannon
5 min	Next Steps	Abby Zier Alyesh

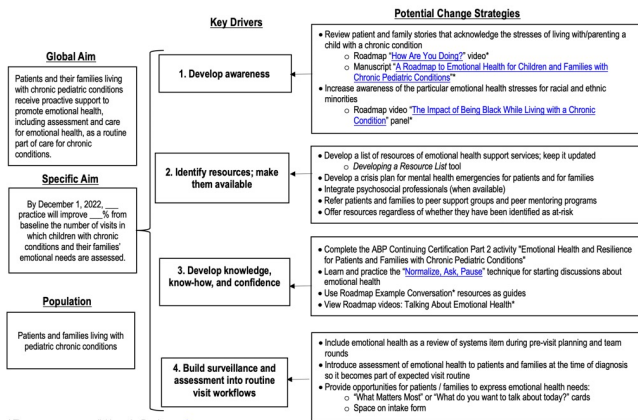
Roadmap College Setup

Carole Lannon

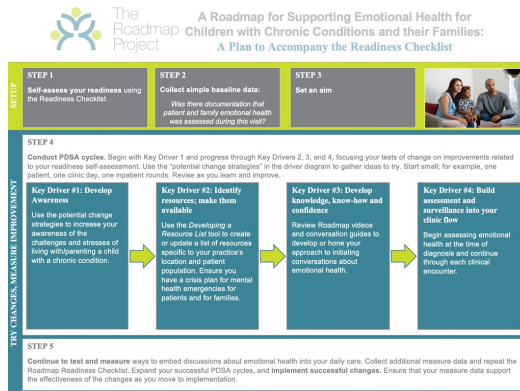


Interconnected Resources for You

Driver Diagram



5-Step Plan



Readiness Checklist

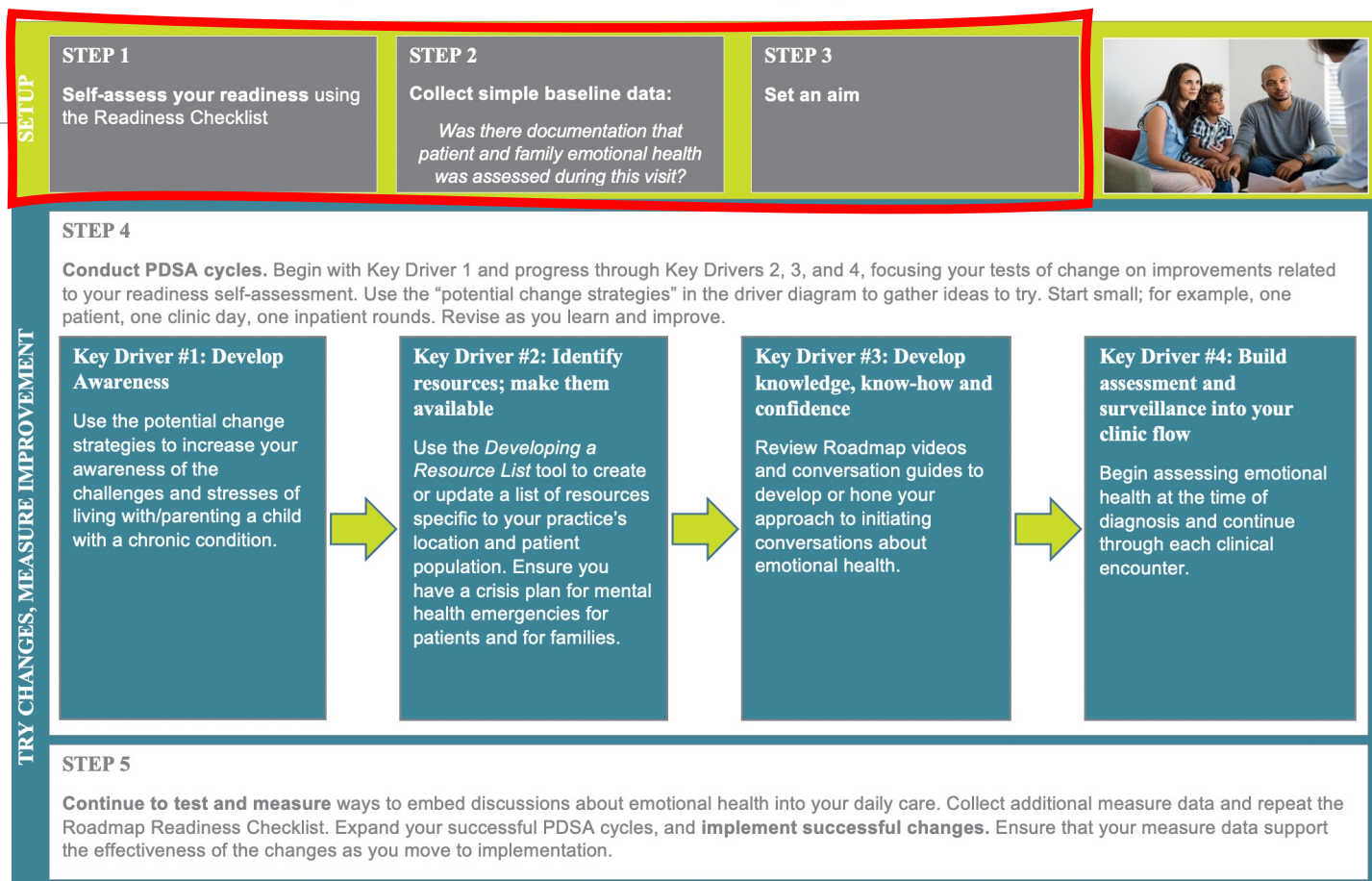
CHECKLIST COMPONENT	0	1	2	3	N/A
Baseline	Not currently	Developing or testing	Part of my individual practice	Across the clinical setting in which I practice	
A. I, and my clinical colleagues and staff with patient or family contact, are aware of and can state <ul style="list-style-type: none"> the stresses 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. Our practice setting has an up-to-date list of resources available to support the emotional health of children with chronic conditions and their families that includes: <ul style="list-style-type: none"> 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. Our 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. Our practice setting has a crisis plan in place to handle mental health emergencies, including suicidality, for family members (e.g., parents)					
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					
F. Providers in our practice build assessment of emotional health into a routine clinic visit					





The
Roadmap
Project

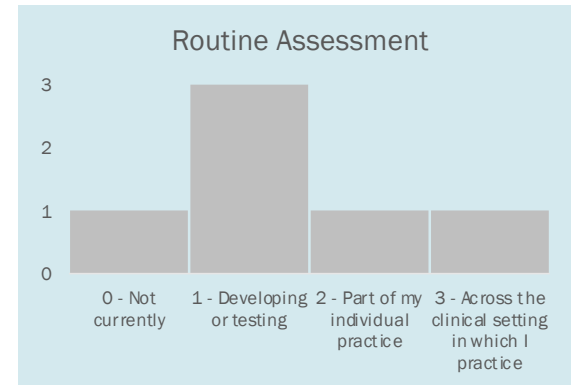
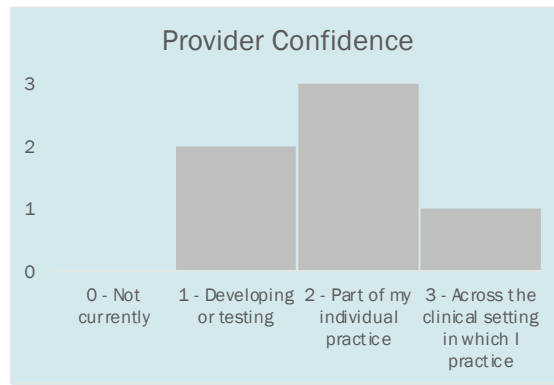
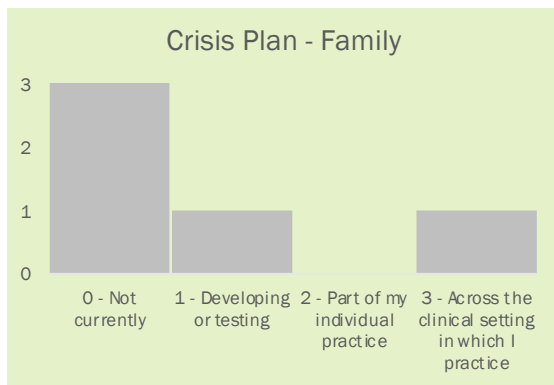
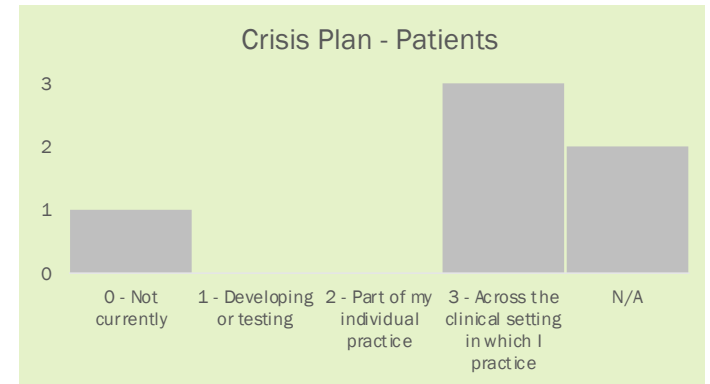
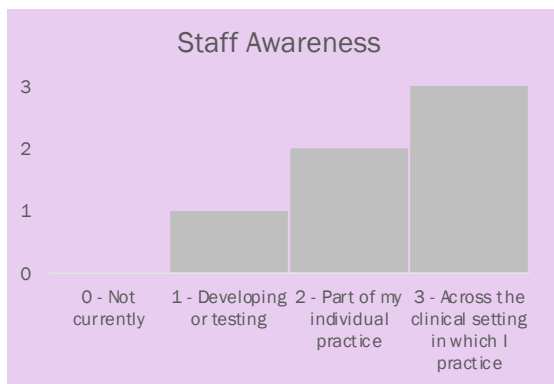
A Roadmap for Supporting Emotional Health for Children with Chronic Conditions and their Families: A Plan to Accompany the Readiness Checklist



The
Roadmap
Project

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Self-Assessed Readiness



Aims

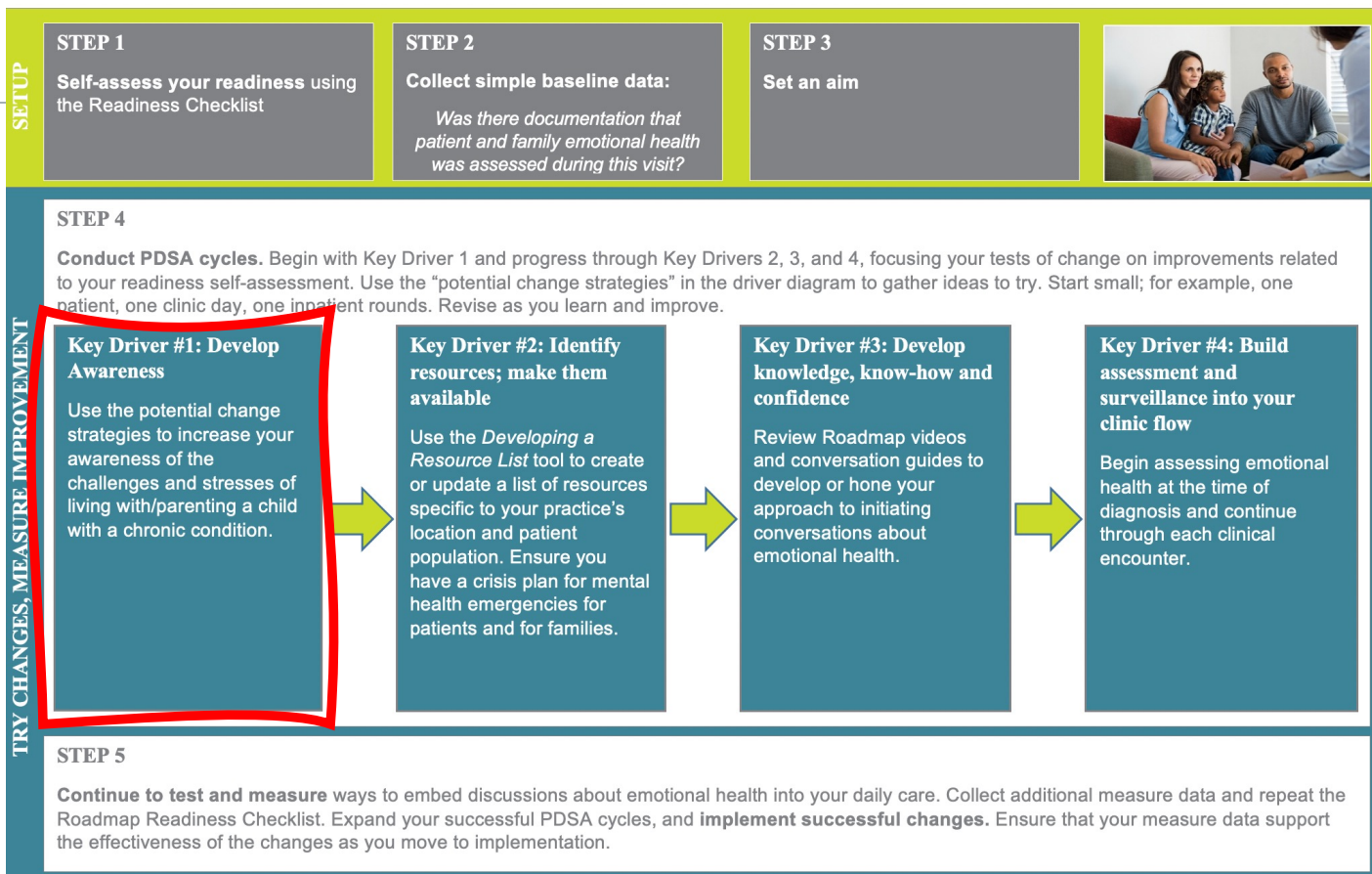
By December 1, 2022, _____ practice will improve _____% from baseline the number of visits in which children with chronic conditions and their families' emotional needs are assessed.

Hospital Practice	Improvement from baseline
LCH Heartest Yard Congenital Heart Center	60%
CHLA Cardiology	20%
Akron Children's Hospital LIFT clinic	30%
NCH Single Ventricle Roadmap Team	60%
Dell Children's Medical Center	80%
Advocate Children's Hospital	50%



The Roadmap Project

A Roadmap for Supporting Emotional Health for Children with Chronic Conditions and their Families: A Plan to Accompany the Readiness Checklist



The Roadmap Project

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Current State of Assessing Emotional Health for Patients and Families

Meg Didier
Melissa Cousino



Meg Didier

- Director of Fontan Patients, Sisters by Heart
- Patient with hypoplastic left heart

Becoming aware of the impact of my CHD


Anxiety
Depression
ADHD
PTSD
Insomnia

Surgical intervention
Doctors appointments – planned/unplanned
Anticipatory grief
Falling behind and losing abilities
Symptoms of my CHD
Financial concerns
Isolation

How emotional health be improved in CHD care practices TODAY?

1. Communication
2. Validation
3. Resources

Communication and Validation

- Specialists become the main point of contact for patients and families
 - Holistic approach to medicine includes physical AND mental/emotional health
 - Create opportunity for open dialog: portal message, clinic visit, etc.
 - Start early, ask often
 - Elaborate and build on conversations
 - Reassurance through data-driven information
 - Ex: higher prevalence of emotional health concerns associated with CHD
- 
- Feeling heard and understood
 - Feeling acknowledged as a “person” rather than just a patient
 - Feeling valued by care team
 - Establish rapport and trust
 - Improve quality of life
 - Increase feelings of self worth
 - Seek treatment options earlier
 - Therapy, medication, etc.

Resources

- In-house and outside services for patients and families
 - Develop a care center specific one pager on emotional health and available services
- Peer-to-peer support
 - Single Ventricle Patient Day hosted by Fontan Outcomes Network
 - National organizations
 - Social media groups
 - Local camps



Melissa Cousino, PhD

- Associate Professor, Pediatrics and Cardiac Surgery
- Director, M-COPE, Psychosocial Services



Disclosures

Funding

NHLBI, K23 HL145096-01

NINR, R21 NR016802-02

Enduring Hearts and Additional Ventures

Pediatric Heart Network



"It's *always about the heart...*

The echo looks good. The labs are great. The biopsy is clean. There are smiles and relief all around.

But, what if I am not good? ***What if I still feel broken inside...*** sometimes thinking life would just be easier if I was not one of the lucky ones... not one of the miracle stories.

And, then the guilt sets in. ***I should feel grateful. I should feel happy!***

Our Goal





No Health Without Mental Health

Mental Health Awareness Month

A National Emergency

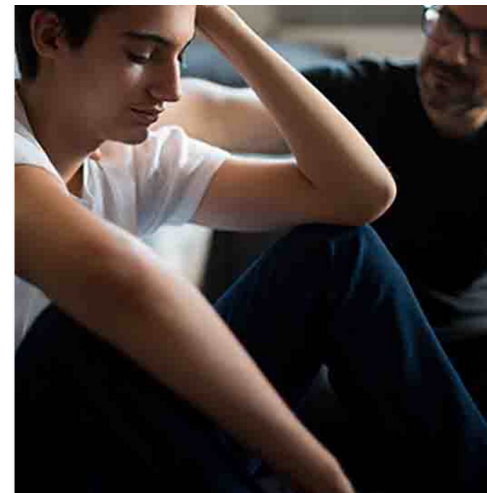
**Pediatric Mental
Health Crisis Reaches
Critical Tipping Point**

American Academy of Pediatrics



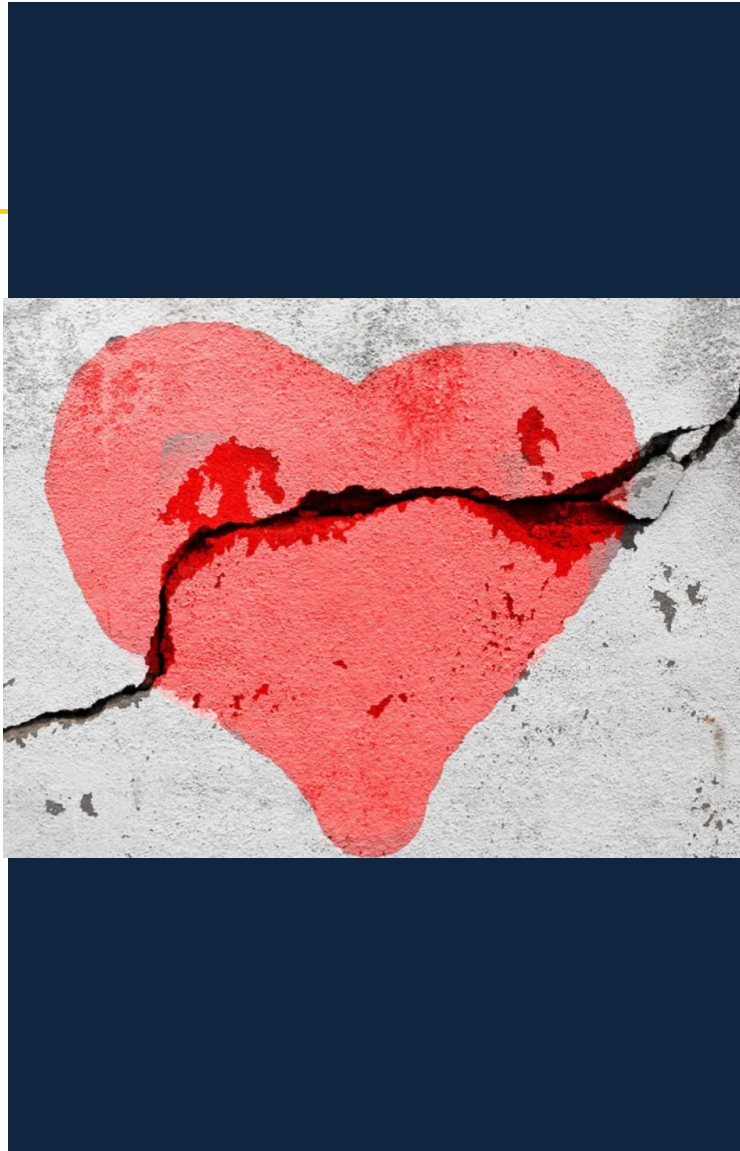
Declaration of a National Emergency for Child and Adolescent Mental Health

October 19, 2021



**AAP, AACAP, CHA Declare National Emergency in
Children's Mental Health**

Child Mental Health



1 in 2
Parent-reported
worsened
mental health

100%
Increase
(doubling) in
youth dep/anx

51%
Increase in ER
visits for teen girl
suicide attempts

24-31%
Increase in ER
visits for mental
health in 5-17yo

C.S. Mott National Poll; Racine et al., 2021; Yard et al., 2021; Leeb et al., 2020; Krass et al., 2021

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175,000

U.S. children have lost a primary caregiver to COVID-19; 65% of COVID-19 orphanage in children of racial/ethnic minority



Circulation

AHA SCIENTIFIC

Psychological
Mind-Heart
A Scientific Statement

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.

g, and the
rt Association

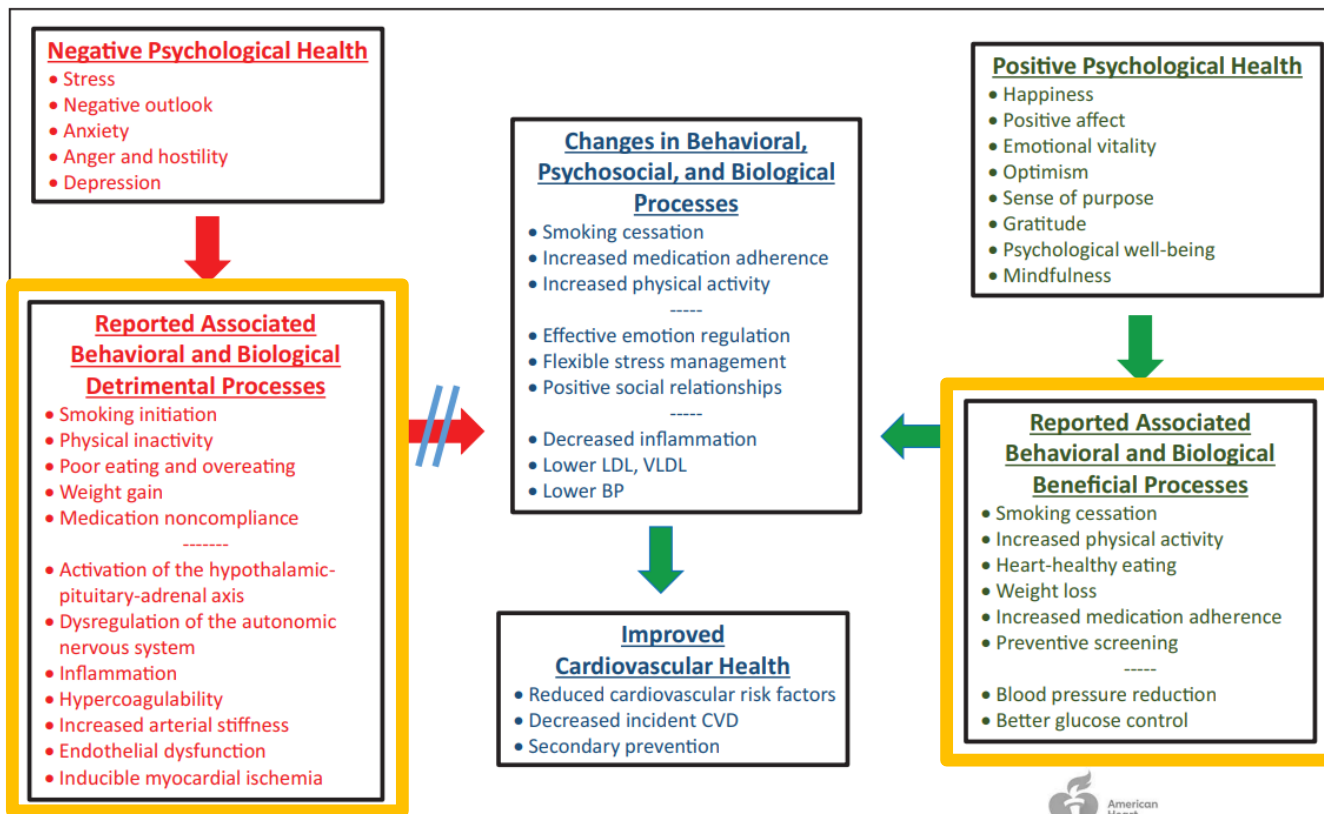


Figure. Negative and positive associations of psychological health and cardiovascular risk and health and potential biologically plausible mechanisms of how improved psychological health can lead to decreased cardiovascular risk.

Figure concept inspired by Levine,² Kubzansky et al,⁵⁴ Rozanski,¹⁶⁶ and many other sources. BP indicates blood pressure; CVD, cardiovascular disease; LDL, low-density lipoprotein; and VLDL, very-low-density lipoprotein.

Mental Health in Pediatric Heart Disease



2 in every 3 or 65% of pediatric patients with single ventricle heart disease experience a mental health condition in their lifetime.



1 in every 2 or 50% of adults with congenital heart disease have a mental health diagnosis, such as depression or anxiety.



Half of parents/families of children with CHD report needing psychosocial care for themselves.

Cousino et al., 2021; Demaso et al., 2017; McCormick et al., 2022; Rea et al., 2021

Mental Health in Pediatric Heart Disease



40% of pediatric patients with a VAD experience a current mental health condition.



Higher rates of anxiety and depression in pediatric heart transplant recipients.

Depression → higher rates of readmission and poorer graft survival 5 years post-tpx.



30-50% of post-transplant patients AND families report persisting, significant psychosocial stress.

Cousino et al., 2021; Demaso et al., 2017; McCormick et al., 2022; Rea et al., 2021



COVID Impact in CHD/ACHD



Pediatric Patients
with Clinically
Significant Stress
Scores

50%



ACHD Patients
with Clinically
Significant
Stress Scores

42%



Caregivers
with Clinically
Significant
Stress Scores

42%

Cousino et al., 2021

Thank You



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[@melissacousino](https://twitter.com/melissacousino)



YOUR TURN

Brief Discussion

What surprised you?

What will stick with you as you think about sharing with your colleagues?

What questions do you have?

CHECKLIST COMPONENT Baseline	0 Not currently	1 Developing or testing	2 Part of my individual practice	3 Across the clinical setting in which I practice	N/A
A. I, and my clinical colleagues and staff with patient or family contact, are aware of and can state <ul style="list-style-type: none"> 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 					

How to Develop an Awareness of Emotional Health Needs Among Clinical Teams

Aliese Sarkissian



Aliese Sarkissian, MD, MBOE

- UNC Children's Assistant Professor, Division of Pediatric Rheumatology
- Site Co-leader, Roadmap Pilot Collaborative



Are you ready to engage
your colleagues?

Start with yourself- what barriers do I see?

- I do not have ...
 - training in emotional health counseling
 - time to ask during the patient visit
 - the emotional health resources to offer
- It is likely your colleagues have the very same ones!
- Present interventions to these barriers in conjunction with the importance of emotional health support for patients with chronic conditions and their families

Intervention: I do not have the training

- Dr. Erica Sood's excellent talk and model : Normalize- Ask- Pause
 - Summarize key points to present to your division
 - Tailor it to your field (e.g. rheumatology patients often have to administer injectable medications, which often leads to anxiety)
- Roadmap Example Conversation resources (1-page tools or videos)
 - Share one video with the group and discuss
- Don't forget to ask your division- they may already be employing ways to ask!

Intervention: I do not have the time

- Most often you will only get a "tip of the iceberg", per Dr. Sood
- If you start early (diagnosis day) it becomes a normal part of the visit, included in the review of systems
- Ask your team how much time (and resources) are spent when emotional health problems result in lack of therapeutic adherence?

Intervention: I do not have resources...

- LISTENING is an intervention!
- You do not have to solve all their problems at one visit, just as you cannot cure their chronic condition at one visit
- Be creative and brainstorm with your division about what you do have
 - Disease foundation websites with peer and family support
 - Ask other divisions what they use in terms of local resources

Share the interventions and circle back to maintain them

- Pilot your talk in your division
 - What other barriers did they identify?
 - What resources did you brainstorm?
- Take it larger to your department
 - Helps identify other “champions” across divisions
- Return to your division
 - Case conference is not only a time to review diagnostic challenges, but also to review total care for patients



Questions for Aliese?

- What resonates for you?



Change ideas

1. Identify personal barriers
2. Identify team barriers
3. Determine who needs to be aware
4. Set aside time with each audience to discuss barriers and solutions
5. Embrace the iterative nature of raising awareness



YOUR TURN

Potential Barriers

Personal

- Training
- Time
- Resources
- Knowledge
- Other?

Team

- Training
- Time
- Resources
- Knowledge
- Other?



Who needs awareness?

- Front desk
- Clinic pod
 - MA
 - Nurse
 - Psychologist
 - Social worker
 - Other clinicians
- Inpatient team
 - Residents and fellows
 - Other clinicians
 - Nurses
 - Psychologist
 - Social worker
- Division

Key message:

1. This is important
2. You might feel like you don't have time or that you don't know how to do this
3. We will learn together and build the skills



Resources to help

Remember, this is iterative

- [Your pre-reading and viewing](#): *Pediatrics* manuscript, How are you doing video, The Impact of Being Black While Living with a Chronic Condition video
- Melissa and Meg's slides
- Addressing Emotional Health: A Self- Assessment
- Your own data



Addressing Emotional Health: A Self-Assessment

These questions will help you evaluate your understanding of emotional health and present example scenarios to help you put learning into practice while caring for patients with chronic conditions and their families. Once complete, compare your answers with the self-assessment key.

Helpful for: Clinicians, training program directors, and trainees

[Download the Self-Assessment](#)

[Download the Self-Assessment Key](#)

Next Steps

Abby Zier Alyesh



Before Webinar #2

Takeaway tests:

- What step can you take to overcome one (or more) of your barriers?
- How can you raise awareness with one of the audiences you identified?

Tasks:

- Visit the Roadmap College participant page to see pre-reading
- Report Month 1 data on REDCap by May 27



Evaluation



Webinar #2

June 9
3-4pm ET

Identify Resources
and Make Them
Available