

## Psychological Stress in Pediatric and Adult Congenital Heart Disease Patients and Caregivers During the COVID-19 Pandemic

The COVID-19 Pandemic has dramatically affected medical care throughout the world. Patients and caregivers of patients with congenital and other pediatric heart diseases have expressed worry about how COVID could affect them. Further, widespread changes in typical medical treatments and care delivery have occurred. Surgery, procedures, and clinic appointments have been reduced in efforts to stop the spread of the virus and preserve hospital resources for COVID-affected patients. With this survey we hope to better understand how care has changed across the world, how it has caused stress for patients and caregivers, and what specific issues have caused the most stress. We will ask a few questions about your/your child's or partner's specific heart disease, about specific changes in cardiology or cardiac surgery appointments and plans, specific concerns related to COVID-19, and some questions about your current level of stress. With this information, we hope to change our care practices during the pandemic to better serve our patients and better understand how to prioritize the backlog of care needs that will be present following the pandemic.

We invite you to participate in a survey research project to help learn more about stress related to cardiology care during the COVID-19 pandemic. This brief, one-time survey should take less than 10 minutes to complete. We appreciate your participation.

Your participation is completely voluntary. Participation is not required. All information will be kept strictly confidential. No link from the survey to you/your child/your partner will be made. **The survey is anonymous.** The results of the survey will be kept indefinitely for use in future studies.

If you agree to complete the questionnaire, read the following statement of consent, and click on the "Start survey" button below which will send you to the web-based survey. Thank you for your help with this project.

I have read the information given above. I understand the meaning of this information. I consent to participate in the project. I am 18 years-old or older. I am completing this survey, and I am a person who has congenital or other pediatric heart disease, or I am the parent or caregiving partner of someone who has heart disease.

- Start Survey
- I do not Consent - Please close window



Please identify yourself

- I am an individual with congenital or other pediatric heart disease
- I am the parent or caregiver of an individual with congenital or other pediatric heart disease
- I am the partner or spouse of > 1 year of an individual with congenital or other pediatric heart disease



What is your child's age in years?

Is your child currently admitted to a hospital?

No

Yes

Where is your child from?

United States of America

Other country



In which region of the USA does your child live?

- Northeast
- Midwest
- South
- West

My child has the following (check all that apply):

- Single ventricle congenital heart disease
- Two ventricle congenital heart disease
- Cardiomyopathy or disease of the heart muscle without structural heart disease
- Status post Heart Transplant



Regarding single ventricle congenital heart disease, at what stage is your child?

- No operation yet
- s/p Stage 1 or shunt or Norwood operation
- s/p hybrid Norwood operation
- s/p Stage II or bidirectional Glenn or hemifontan operation
- s/p Fontan
- Other (write in)

Has your child had heart surgery in the past?

Yes

No



Has your child had heart surgery in the past 6 months?

Yes

No

Has your child had more than 1 heart surgery in the past at any time?

Yes

No



How many heart surgeries has your child had?

Did your child have a recent or upcoming surgery planned?

Yes

No



When was / is the surgery planned?

- March-July 2020
- July-Sept 2020
- October 2020-March 2021
- After March 2021

Has your child had a surgery date postponed due to the COVID pandemic?

Yes

No





If your child has a surgery scheduled that has not been postponed, are you concerned about the potential impact of COVID pandemic on the surgery?

Yes

No

Did your child have a recent or upcoming cardiac catheterization planned?

Yes

No



When was the cardiac catheterization planned?

- March-July 2020
- July-Sept 2020
- October 2020-March 2021
- After March 2021

Has your child had a cardiac catheterization postponed due to the COVID pandemic?

Yes

No



If your child has a cardiac catheterization that has not been postponed, are you concerned about the potential impact of COVID pandemic on the procedure?

Yes

No

Did your child have a recent or upcoming cardiology clinic appointment planned?

Yes

No



When was the upcoming cardiology clinic appointment?

- March-July 2020
- July-Sept 2020
- October 2020-March 2021
- After March 2021

Has your child had a clinic date postponed due to the COVID pandemic?

Yes

No



If your child has a clinic date scheduled that has not been postponed, are you concerned about the potential impact of COVID pandemic on attendance in clinic?

Yes

No

Have you received information about rescheduling the appointment until after the pandemic?

Yes

No



Has your child had an appointment changed from in-person to a video visit or phone call due to COVID-19?

Yes

No



Did you feel the virtual visit was adequate to cover your needs?

Yes

No



If you answered No, please explain why

Have you received general information about COVID-19 from your child's cardiologist/surgeon/center?

Yes

No

Have you received information specific-to-you about COVID-19 from your child's cardiologist/surgeon/center?

Yes

No

Have you received general information about COVID-19 from a heart disease support group, advocacy group, or social media group?

Yes

No





If you answered Yes, where did you receive this information? (check all that apply)

- Fact sheet
- Article
- Conference
- Webinar



Please indicate which of the following concerns you as it relates to your child's heart care and health:

	Not concerned	A little concerned	Somewhat concerned	Moderately concerned	Very concerned
Obtaining medications during the pandemic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being seen in person by cardiology provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not being able to speak to or reach my cardiology provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Postponed surgery or procedure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Postponed clinic visit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Challenges rescheduling surgery or procedure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Harm to your child due to postponed medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Death of your child due to postponed medical care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coming to hospital or clinic for in-person care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How concerned are you about your child becoming ill from COVID-19?

- Not concerned
- A little concerned
- Somewhat concerned
- Moderately concerned
- Very concerned

How concerned are you about personally becoming ill from COVID-19?

- Not concerned
- A little concerned
- Somewhat concerned
- Moderately concerned
- Very concerned

How concerned are you about who will take care of your child if you get sick?

- Not concerned
- A little concerned
- Somewhat concerned
- Moderately concerned
- Very concerned

How concerned are you about the impact of COVID-19 on personal finances?

- Not concerned
- A little concerned
- Somewhat concerned
- Moderately concerned
- Very concerned



Please indicate how much each of the following your child has experienced since COVID-19 outbreak started

	None	Mild	Mild- Moderate	Moderate	Severe
Anxiety/Worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sadness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anger	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Changes in behavior (tantrums, attention problems, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulties taking medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate which of the following would be helpful to your child to best support you during this stressful time and the months to follow (check all that apply):

- More regular video or phone check-ins with cardiology provider
- More information / resources on COVID-19 and heart care
- More information / resources on COVID-19 and managing mental health/stress
- Increased access to social work services
- Increased access to psychology / therapy services
- Increased access to support group
- Don't know / None of the above



NIH Toolbox Item Bank / Fixed Form v.2.0 -- Perceived Stress (Ages 18+)

**Perceived Stress (Ages 18+) -- Item Bank / Fixed Form**

**Please respond to each question or statement by selecting one option per row.  
Report on your own stress levels, not those of your child.**

**In the past month...**

	Never	Almost Never	Sometimes	Fairly Often	Very Often
How often have you been upset because of something that happened unexpectedly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you felt that you were unable to control the important things in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you felt nervous and "stressed"?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you felt confident about your ability to handle your personal problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you felt that things were going your way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Almost Never	Sometimes	Fairly Often	Very Often
How often have you found that you could not cope with all the things that you had to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you been able to control irritations in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you felt that you were on top of things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you been angered because of things that happened that were outside of your control?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often have you felt difficulties were piling up so high that you could not overcome them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**Psychological Stress Experiences - Short Form 8a**

**Please respond to each question or statement by selecting one option per row.**

**In the past 7 days...**

	Never	Rarely	Sometimes	Often	Always
My child felt stressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt that his/her problems kept piling up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt overwhelmed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt unable to manage things in his/her life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Everything bothered my child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt under pressure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child had trouble concentrating	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child felt he/she had too much going on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Thank you for completing this survey.

If you or your child or partner are experiencing a mental health emergency, please contact 911 or your local emergency department immediately. You may also utilize the National Suicide Prevention Line for any additional mental health emergencies at 1-800 273-8255 or the Crisis Text Line by texting "HOME" to 741741.

