

SUPPLEMENTAL MATERIAL

Table S1. Survey About Caring for Children with Heart Disease – Parent.

Where is this survey being administered?

- Cardiac ICU
- Cardiology ward
- Other _____

As part of this initiative, there is a doctor survey as well. Can you tell us who at Boston Children's Hospital you consider to be your child's heart doctor? _____

How long have you known about your child's heart problem?

- <1 month
- 1 to 6 months
- 6 months to 1 year
- >1 year

At what age was your child diagnosed with a heart problem?

- Before he/she was born
- In the first week of life
- At age _____

Has your child ever been treated at a hospital other than Boston Children's Hospital for his/her heart condition?

- YES, Where? _____
- NO

YOUR CHILD'S MEDICAL ISSUES

We would first like to ask you about some of the medical problems your child may be experiencing.

In the past week, how well prepared have you been for the medical problems your child is experiencing?

- Very prepared
- Somewhat prepared
- A bit prepared
- Not at all prepared

How has your child been obtaining nutrition in the past week?

- Eats by mouth
- By feeding tube
- Eats by mouth and feeding tube
- Nutrition through IV
- Not receiving nutrition
- Other _____

Which of the following services, if any, have contributed towards improvement in your child's quality of life in the past week? *Check all that apply.*

- Child life specialist
- Hospital school teacher
- Psychology/Psychiatry
- Social work
- Spiritual advisor/Chaplain
- Palliative care/PACT team clinician
- Other (please describe: _____)

What best describes your child's current functional status (i.e. symptoms and activity level)?

- No limitation of physical activity
- Slight limitation of physical activity
- Marked limitation of physical activity
- Unable to carry on any physical activity without discomfort

In the past week, to what degree do you feel your child is experiencing symptoms related to his/her heart condition?

- A great deal
- A lot
- Somewhat

- A little
- Not at all

In the last week, has your child experienced any of the following symptoms?

	Yes	No
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>

If yes, how much did your child suffer from each symptom?

	A great deal	A lot	Somewhat	A little	Not at all
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

During the past week, has your child received treatment or interventions specifically for this symptom?

	Yes	No
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>

If yes, how well did the treatment work in decreasing these symptoms?

	Successfully	Somewhat successfully	Not successfully
Breathing difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty feeding or poor appetite	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nausea/Vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thirst	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low Energy or Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleep Disturbance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety or Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Irritability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall, to what extent do you feel that your child's medical team has asked about his/her symptoms over the past week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, to what extent do you feel that your child's medical team has addressed his or her symptoms over the past week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Which of the following describes the amount of suffering your child had from his/her symptoms in the last week? Would you say he/she suffered:

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Please add any additional information regarding your child's symptoms: _____

RECENT TREATMENTS OR INTERVENTIONS

Overall, which of the following describes the amount of suffering you perceive your child is experiencing as a result of treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, which of the following describes the amount you feel that your child is benefitting as a result of treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

In the last month, did your child undergo cardiac catheterization?

- Yes
- No

Which of the following describes the amount of suffering you perceive your child is experiencing as a result of undergoing cardiac catheterization?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Which of the following describes the amount that you feel your child is benefitting as a result of undergoing cardiac catheterization for his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Please describe in what way(s) he/she is suffering and/or benefitting from undergoing cardiac catheterization? _____

In the last month, did your child undergo cardiac surgery?

- Yes
- No

Which of the following describes the amount of suffering you perceive your child is experiencing as a result of undergoing cardiac surgery?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Which of the following describes the amount that you feel your child is benefitting as a result of undergoing cardiac surgery for his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Please describe in what way(s) he/she is suffering and/or benefitting from undergoing cardiac surgery? _____

In the past month, did your child undergo any non-cardiac procedure?

- Yes (What type? _____)
- No

Which of the following describes the amount of suffering you perceive your child has experienced as a result of undergoing this non-cardiac procedure?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Which of the following describes the amount that you feel your child is benefitting as a result of undergoing this non-cardiac procedure for his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Please describe in what way(s) he/she is suffering and/or benefitting from this non-cardiac procedure? _____

PROGNOSIS AND GOALS OF CURRENT CARE

You will now be asked some questions regarding your current goals and expectations for your child. We ask that you base your answers on how you feel that your child is doing at this point in time, based on all of the information you have today.

How would you describe the quality of care delivered by your child's care team during the past month?

- Excellent
- Very good
- Good
- Fair
- Poor

How well do you feel that you understand the likely course of your child's heart disease (i.e. prognosis)?

- Extremely well
- Well
- Somewhat
- A little bit
- Not well at all

How likely do you think it will be that your child's heart condition will require lifelong interventions or treatment?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for your child to have limitations in physical activity (such as difficulties exercising), compared with what you would expect if your child did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for your child to have limitations in learning, development, and behavior (such as difficulty with schoolwork), compared with what you would expect if your child did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

How often do you worry that your child will get sicker?

- Never
- A little
- Sometimes
- A lot
- All the time

I am unsure if my child is getting better or worse.

- Strongly disagree
- Disagree
- Undecided
- Agree
- Strongly agree

Have you ever had a conversation with your child's healthcare team that included discussion on what would happen if your child got sicker?

- Yes
- No

Was this conversation helpful?

- Yes
- No
- Not applicable

Comments: _____

What is your current understanding of how long your child will live?

- Days to weeks
- Weeks to months
- Months to 1 year
- Several years
- Into adulthood
- Normal life expectancy

Comments: _____

To what extent does the day to day management of your child's heart condition make it challenging to talk about long-term issues such as prognosis?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

How likely do you think it is that your child will still be in Boston Children's Hospital one month from now?

- Very likely
- Somewhat likely
- Not likely

YOUR CHILD'S CARE TEAM & DELIVERY OF NEWS

During the past month, has your child's medical provider had a conversation with you during which he/she specifically delivered new information regarding your child's prognosis or course of treatment?

- Yes
- No

Would you please share some details of what was discussed during this conversation? _____

To what extent did you feel this discussion was open and honest?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

To what extent did you feel this discussion was confusing?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

During this discussion, were you able to express your hopes?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

If so, were your hopes adequately addressed?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Were you able to express your worries?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

If so, were your worries adequately addressed?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Did you need to make a decision about your child's medical care following receipt of this new information?

- Yes
- No
- Not applicable

To what extent did you feel prepared to make this decision?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

To what extent did you feel supported in making this decision?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Is there anything else you would like to add regarding how news was given to you and your family? _____

During the last month, how often did you receive conflicting information from different health professionals?

- Always
- Most of the time
- Some of the time
- Rarely
- Never

Please add any additional comments: _____

How do you feel about the number of different people who give you information regarding your child's heart condition during the past month? Would you say the number of people is:

- Too many
- Just enough
- Not enough

How often were you the one to tell health professionals the medical details of your child's condition because they didn't seem to know during the past month?

- Always
- Most of the time
- Some of the time
- Rarely
- Never

To what extent do you feel that your expectations for your child's prognosis are the same as the expectations of your child's care team?

- A great deal
- A lot
- Somewhat
- A little
- Not at all
- Not applicable

Have you ever felt that your child's care team knows something about your child's overall prognosis that you might not know?

- Yes (Describe: _____)
- No

Would you like to know more about your child's prognosis?

- Yes
- No

Overall, how adequate has communication between you and your child's care team been during the past month?

- Excellent
- Very good
- Good
- Fair
- Poor

What have you found to be the most effective way for you to receive information from the care team about your child's heart condition?

- Attending bedside rounds
- Scheduled formal family meetings
- Informal bedside conversations/updates

When making decisions regarding your child's care, which of the listed caregiver's opinion do you regard as the most important in guiding these decisions? Please choose only ONE answer.

- Your child's primary cardiologist
- Intensive Care Unit physician
- Cardiac Surgeon
- Family member
- Pediatrician
- Other _____

What other sources do you use to obtain information about your child's heart condition? Check all that apply.

- Talking with other parents of children with heart disease via social media
- Talking with other parents of children with heart disease in person
- Talking with other parents of children with heart disease over the phone
- Searching the internet (Which websites? _____)
- Reading books

CURRENT PARENT SOCIO-DEMOGRAPHIC CHARACTERISTICS

We would now like to ask you some information about yourself. This information will remain confidential.

What is your relationship with the patient?

- Mother
- Father

What year were you born? _____

Choose the response that most nearly describes the highest degree you obtained:

- Less than high school
- High school diploma or equivalent (GED)
- College degree
- Graduate degree

Which of the following groups best describes your racial background?

- American Indian / Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other (please specify): _____

Which group best describes your ethnic background?

- Hispanic or Latino
- Not Hispanic or Latino

Please describe your marital status

- Not Married
- Married or living with partner

Earlier studies by our group have shown that many families experience financial stress during their child's hospitalization. Information about finances from families like yours will help us be sure that finances do not impact a child's experience during treatment.

Survey responses will be kept confidential and not shared with your treatment team. No information will be presented in any way that would permit identification of your family or child.

Please answer these questions thinking about the 6 months before your child's current hospitalization.

In the last 6 months, was there a time when you were not able to pay the rent or mortgage on time because of financial difficulties?

- Yes
- No

How many people are currently living in your household, including yourself? _____

How many bedrooms are in your home? _____

“Within the past 6 months we worried whether our food would run out before we got money to buy more.”

- Often true
- Sometimes true
- Never true
- Don't know or refused

“The food that we bought just didn't last, and we didn't have the money to get more.”

- Often true
- Sometimes true
- Never true
- Don't know or refused

Which of these categories best describes your total combined family income for the past 12 months? This should include income (before taxes) from all sources, wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relatives (including child payments and alimony), etc. Please give your best estimate: _____

Please provide your zip code prior to your child's hospitalization: _____

During your child's hospitalization, have you been able to stay locally?

- Yes
- No

If yes, where are you staying? (select all that apply)

- In a local hotel
- With local relatives
- In Patient Family Housing
- At bedside
- A sleep space
- Other, please describe: _____
- Not applicable

If no, is it because? (select all that apply)

- Live close enough
- Local hotels are too expensive
- Affordable options through hospital resources are not available
- Work
- Commitments at home
- Other, please describe: _____
- Not applicable

Table S2. Survey About Caring for Children with Heart Disease – Physician.

SYMPTOMS AND QUALITY OF LIFE

If this patient is currently < 8 years of age, what best describes the patient's current functional status according to the Modified Ross Heart Failure Classification for Children?

- Class I: Asymptomatic
- Class II: Mild tachypnea or diaphoresis with feeding (infants) or mild dyspnea on exertion (older children)
- Class III: marked tachypnea or diaphoresis with feeding (infants) or marked dyspnea on exertion (older children) or prolonged feeding times with growth failure
- Class IV: Symptoms such as tachypnea, retractions, grunting, or diaphoresis at rest

If this patient is currently >8 years of age, what best describes the patient's current functional status according to the New York Heart Association Classification?

- Class I: No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or shortness of breath.
- Class II: Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, shortness of breath.
- Class III: Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
- Class IV: Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

In the past week, to what extent is this patient experiencing symptoms attributable to his/her heart condition?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, to what extent do you feel that the team has addressed this patient's symptoms in the last week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Which of the following describes the amount of suffering you perceive the patient is experiencing as a result of his/her symptoms in the last week?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, which of the following describes the amount of suffering you perceive the patient is experiencing as a result of receiving treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, which of the following describes the amount that you feel the patient is benefitting as a result of receiving treatment/interventions for his/her heart condition at this time?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

GOALS OF CURRENT CARE AND PROGNOSIS

In the past week, how well prepared do you feel that this patient's parents have been for the medical problems their child is experiencing?

- Very prepared
- Somewhat prepared
- A bit prepared
- Not at all prepared

How well do you think this patient's family understands their child's prognosis?

- Extremely well
- Well
- Somewhat
- A little bit
- Not well at all

How likely do you think it is for this patient's heart condition to require lifelong interventions or treatment?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for this patient to have limitations in physical activity (such as difficulties exercising), compared with what you would expect if this patient did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

How likely do you think it will be for this patient to have limitations in learning, development, and behavior (such as difficulty with schoolwork), compared with what you would expect if this patient did not have a heart condition?

- Very likely
- Somewhat likely
- Not likely

Have you ever had a conversation with this patient's family that included discussion on what would happen if their child got sicker?

- Yes
- No

Was this conversation helpful?

- Yes
- No

What is your current understanding of how long the patient will live?

- Days to weeks
- Weeks to months
- Months to 1 year
- Several years
- Into adulthood
- Normal life expectancy

What makes this question difficult to answer? _____

Would you be surprised if this child died within the next year?

- Yes
- No

How likely do you think it is that this patient will still be at Boston Children's Hospital one month from now?

- Very likely
- Somewhat likely
- Not likely

COMMUNICATION & DELIVERY OF NEWS

To what extent does the day to day management of this patient's heart condition make it challenging to talk about long-term issues such as prognosis?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

During the last month, how often do you think the family received conflicting information from different health professionals?

- Always
- Most of the time
- Some of the time
- Rarely
- Never

To what extent do you feel that your expectations for this patient's prognosis are the same as the expectations of the patient's family?

- A great deal
- A lot
- Somewhat
- A little
- Not at all

Overall, how adequate do you feel the team's communication with this family has been in the past month?

- Excellent
- Very good
- Good
- Fair
- Poor

What have you found to be the most effective way for this family to receive information from the care team about their child's heart condition?

- Attending bedside rounds
- Scheduled formal family meetings
- Informal bedside conversations/updates

Do you think that participating in this study has changed the way that you communicate with this family?

- A great deal
- A lot
- Somewhat
- A little
- Not at all