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TO: Nancy McCabe, RN
Principal Investigator
Graduate Nursing

DATE: July 12, 2013

RE: **Expedited Approval**
IRB00067006
Antecedents and Outcomes of Self-Care in Adult Congenital Heart Disease

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory categories F(4, 5, and 7) as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on 7/11/2013 and granted approval effective from **7/11/2013** through **7/10/2014**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this approval:

- Study Protocol, undated, uploaded 6/1/2013
- Consent and Authorization documents:
 - Consent form, version date 7/1/2013
 - HIPAA Authorization form, version date 7/1/2013
 - Revocation letter, version date 7/1/2013
- Study Instruments:
 - Participant Screening and Enrollment form
 - Health Distress form
 - Chronic Disease Self-Efficacy Scales
 - Parental Bonding Instrument
 - Patient Health Questionnaire (PHQ-9)
 - Six Minute Walk Test Score Sheet
 - Personal Health Passport
 - Self-care Index for Adults with Congenital Heart Defects
 - Demographic Survey - Chart Review
 - Demographic Survey
 - Health Resource Use Diary
 - QoL/Health Scales

Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at www.irb.emory.edu, immediately,

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promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.

Before implementing any change to this protocol (including but not limited to sample size, informed consent, and study design), you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you

Sam Roberts, BA CIP
Senior Research Protocol Analyst

This letter has been digitally signed

CC:	Jennings	Staci	MedCardio
	Book	Wendy	MedCardio
	Butler	Javed	MedCardio
	Dunbar	Sandra	Nursing - Main
	Higgins	Melinda	Nursing - Main
	Reilly	Carolyn	Nursing - Main

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: <http://www.irb.emory.edu/>
An equal opportunity, affirmative action university

Emory University
Consent to be a Research Subject

Title: Antecedents and Outcomes of Self-care in Adults with Congenital Heart Defects

Principal Investigator: Nancy McCabe, RN, BSN, BA, Nell Hodgson Woodruff School of Nursing, Emory University

Funding Source: National Institute of Nursing Research Predoctoral Grant

Introduction

You are being asked to be in a nursing research study. This form tells you what you need to think about before you agree to be in the study or not. **It is entirely your choice. If you decide to take part, you can change your mind later and withdraw from the research study. When filling out study surveys, you can skip any questions that you do not wish to answer.** Please read this consent form carefully. If you agree, sign this form, giving your written consent to be in this study.

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to be in this study. By signing this form you will not give up any legal rights. You will also continue to receive the same quality of care by your healthcare provider whether or not you take part in this study.

Study Overview

This study has two main purposes:

1. To understand what helps adults with congenital heart defects to manage their heart condition (self-care).
2. To understand how self-care can improve the health and well-being of adults with congenital heart defects.

Procedures

Everyone in this study will take part in the following activities:

- Complete surveys in an online computer survey or in a paper packet. It is your choice.
- At your next clinic visit, walk as far as you can along a level hallway for 6 minutes.
- Keep track of how often you use the healthcare system (doctor visits, hospitalizations, and emergency room visits,) for 3 months.

The principal investigator is looking for 120 adults with congenital heart defects to be in this study. You and other adults with congenital heart defects have been selected because you attend the Emory Adult Congenital Heart Clinic and qualify for this study. Everyone who qualifies has been mailed a letter of invitation to join the study.

In your invitation letter, you have also received this consent form, a HIPAA authorization form, and a revocation letter. If you decide not to be in this study, contact Nancy McCabe, the principal investigator and discard all of the paperwork you received. We will no longer consider you a potential participant. If you decide to take part in this study after reading this whole form, contact the principal investigator. She will give you a link to fill out the surveys online using a computer. You may also request paper surveys that you can fill out at your next clinic visit. Bring all forms with you to your next clinic visit.

A nurse researcher will meet you at your next clinic visit to collect these forms, sign this consent and HIPAA forms, and conduct a simple walking test. For the walking test, you will walk at a comfortable pace along a level hallway for 6 minutes. You may rest or stop at any time. After your clinic visit, a nurse researcher will contact you by telephone or e-mail (your choice) once a month for 3 months to collect information on how often you used the healthcare system.

Risks and Discomforts

There are few risks to you for being in this study. There is a slight chance you might feel stressed or distressed after completing the surveys. One of the surveys is about depression. If your score shows that you have moderate depression, we will tell you and give you information on getting help. If your score shows that you have severe depression, we will tell you and your healthcare provider and also give you information on getting help. On rare occasions during the walking test, participants may feel short of breath or chest pain. The walking test is closely monitored by trained health care personnel and is only done after a short physical exam including taking your blood pressure, heart rate, and discussing your symptoms. You may stop and rest if needed. Also, your heart rate and oxygen levels will be monitored during the test using an oxygen monitor placed on your finger.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about how adults with congenital heart defects manage their heart condition and how that helps improve their health. The study results may be used to help others in the future.

Compensation

You will be given a \$10 gift card and a free valet parking voucher at your clinic visit. You will get another \$10 gift card at the end of the study. We will give you \$20 in gift cards and you will receive free parking at your clinic visit if you complete this study.

Confidentiality

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include the Emory Institutional Review Board and the Emory Office of Research Compliance. Study funders may also look at your study records. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Study Information Will Go Into Medical Record:

If you are or have ever been an Emory Healthcare patient, you have an Emory Healthcare medical record. If you agree to be in this study, a copy of the consent form and HIPAA form that you sign will be placed in your Emory Healthcare medical record. Emory Healthcare may create study information about you that can help Emory Healthcare take care of you. This includes the results of your walking test. Anyone who has access to your medical record will be able to see the results of your walking test. The confidentiality of this study result will be protected by laws like the HIPAA Privacy Rule. On the other hand, some state and federal laws and rules may not protect the research information from disclosure. Study records can be opened by court order. They may also be produced in response to a subpoena or a request for production of documents.

Costs

There are no costs to you associated with this study.

Voluntary Participation and Withdrawal from the Study

You have the right to leave a study at any time without penalty. You may refuse to do any procedures you do not feel comfortable with, or answer any questions that you do not wish to answer. Should you withdraw from the study, you can request that your information not be used by completing the Revocation Letter.

Contact Information

Contact Nancy McCabe at (404) 234-1574 or nmccabe@emory.edu:

- if you have any questions about this study
- if you want to be in this study
- if you have questions, concerns or complaints about this study

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at <http://www.surveymonkey.com/s/6ZDMW75>.

Written Consent Documentation For Participation

Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

Name of Subject

Signature of Subject

Date Time

Signature of Person Conducting Informed Consent Discussion

Date Time

Emory University Research Subject HIPAA Authorization to Use or Disclose Health Information that Identifies You for a Research Study

Title: Antecedents and Outcomes of Self-care in Adults with Congenital Heart Defects

Principal Investigator: Nancy McCabe, RN, BSN, BA, Nell Hodgson Woodruff School of Nursing, Emory University

Introduction

The privacy of your health information is important to us. We call your health information that identifies you, your "protected health information" or "PHI." To protect your PHI, we will follow federal and state privacy laws, including the Health Insurance Portability and Accountability Act (HIPAA). We refer to all of these laws in this form as the Privacy Rules. This form explains how we will use your PHI for this study.

Please read this form carefully and if you agree with it, sign it at the end.

Description of Research Study

This study has two main purposes:

1. To understand what helps adults with congenital heart defects to manage their heart condition (self-care).
2. To understand the relationship between self-care and health outcomes (symptom burden, quality of life, functional health status, and health resource use).

Researchers will gather data from questionnaires and a simple walking test that lasts six minutes.

PHI That Will Be Used/Disclosed

The PHI that we may use or disclose (share) for this research study includes:

- Your medical record while being treated at Emory Healthcare, including but not limited to:
 - Cardiology Records
 - Medical history
 - Laboratory/diagnostic tests
 - Updated contact information
 - Hospital and/or Emergency room visits

Purposes for Which Your PHI Will Be Used

If you sign this form, you give us your permission to use your PHI for the conduct and oversight of this research study.

People That Will Use or Disclose Your PHI and Purpose of Use/Disclosure

Different people and groups will use and disclose your PHI. They will do this only in connection with the research study. The following persons or groups may use and/or disclose your PHI:

- The Principal Investigator and the research staff.
- The Principal Investigator may use other people and groups to help conduct the study. These people and groups will use your PHI to do this work.
- The following groups may also use and disclose your PHI. They will do this to make sure the research is done correctly and safely. The groups are:
 - The Emory University Institutional Review Board

- The Emory University Office of Research Compliance
- Research monitors and reviewers

We will use or disclose your PHI when we are required to do so by law. This includes laws that require us to report child abuse or elder abuse. We also will comply with legal requests or orders that require us to disclose your PHI. These include subpoenas or court orders.

Expiration of Your Authorization

As this is a research study, your authorization will not expire. You may, however, revoke your authorization later.

Revoking Your Authorization

You do not have to sign this form. Even if you do, at any time later on you may revoke (take back) your permission. If you want to do this, you must write to:

Nancy McCabe
School of Nursing
Emory University
1520 Clifton Road, NE
Atlanta, GA 30322

After that point, the researchers would not collect any more of your PHI. But they may use or pass along the information you already gave them so they can follow the law, protect your safety, or make sure the research was done properly. If you have any questions about this, please ask.

Other Items You Should Know

If we disclose information to people who do not have to follow the Privacy Rules, your information will no longer be protected by the Privacy Rules. People who do not have to follow the Privacy Rules can use or disclose your information with others without your permission if they are allowed to do so by the laws that cover them. Let us know if you have questions about this.

We will put a copy of your signed informed consent form for the research study and your signed HIPAA Authorization form into any medical record that you may have with Emory Healthcare facilities.

During the study you will generally not have access to records related to the research study. This is to preserve the integrity of the research. You may have access to these records when the study is complete. These records may include research related PHI your health care providers use to make decisions about your care. If necessary for your care, this information may be available to your doctor before the end of the study.

If identifiers are removed from your PHI, then the remaining information will not be subject to the Privacy Rules. It may be used or disclosed with other people or organizations, and/or for other purposes.

Contacts

If you have any questions regarding the study, you may call Nancy McCabe at (404) 234-1574.

If you have any questions about the study, or your rights as a study subject, you may contact the Emory University Institutional Review Board at 404-712-0720 or 1-877-503-9797, by email at irb@emory.edu.

Authorization

A copy of this form will be given to you.

Signature of Study Subject

Date

Time

Printed Name of Study Subject

Signature of Person Obtaining Authorization

Date

Time

Printed Name of Person Obtaining Authorization

Date

Time

Incentives

Please complete the survey below.

Thank you!

MRN

First Name

Last Name

Street, City, State, ZIP

Phone number

(Include Area Code)

Date of birth

Age (years)

E-mail

SIMPLE: Native disease Isolated congenital aortic valve disease Isolated congenital mitral valve disease (eg, except parachute valve, cleft leaflet) Small atrial septal defect Isolated small ventricular septal defect (no associated lesions) Mild pulmonary stenosis Small patent ductus arteriosus Repaired conditions Previously ligated or occluded ductus arteriosus Repaired secundum or sinus venosus atrial septal defect without residua Repaired ventricular septal defect without residua MODERATE: Aorto-left ventricular fistulas Anomalous pulmonary venous drainage, partial or total Atrioventricular septal defects (partial or complete) Coarctation of the aorta Ebstein's anomaly Infundibular right ventricular outflow obstruction of significance Ostium primum atrial septal defect Patent ductus arteriosus (not closed) Pulmonary valve regurgitation (moderate to severe) Pulmonary valve stenosis (moderate to severe) Sinus of Valsalva fistula/aneurysm Sinus venosus atrial septal defect Subvalvular AS or SupraAS (except HOCM) Tetralogy of Fallot Ventricular septal defect with: SEVERE: Conduits, valved or nonvalved Cyanotic congenital heart (all forms) Double-outlet ventricle Eisenmenger syndrome Fontan procedure Mitral atresia Single ventricle (also called double inlet or outlet, common, or primitive) Pulmonary atresia (all forms) Pulmonary vascular obstructive disease Transposition of the great arteries Tricuspid atresia Truncus arteriosus/hemitruncus Other abnormalities of atrioventricular or ventriculoarterial connection not included above (ie, crisscross heart, isomerism, heterotaxy syndromes, ventricular inversion)

moderate

severe

Name of Primary Heart Defect

- AS
- ASD
- AVC
- BAV
- Cardiomyopathy
- CoArc
- Coronary anomaly
- DILV
- DORV
- Ebsteins anomaly
- Eisenmenger syndrome
- Heterotaxy
- HLHS
- HRHA
- Interrupted aortic arch
- Kawasaki
- Long QT
- LV non-compaction
- LVOTO
- MR
- MS
- MV Prolapse
- PA
- PAPVR
- PDA
- PFO
- PR
- PS
- RVOTO
- TA
- TAPVR
- TGA-D
- TGA-L
- TOF
- TR
- Truncus
- VSD
- Other

Name of Secondary Heart Defects

- AS
- ASD
- AVC
- BAV
- Cardiomyopathy
- CoArc
- Coronary anomaly
- DILV
- DORV
- Ebstein's anomaly
- Eisenmenger syndrome
- Heterotaxy
- HLHS
- HRHA
- Interrupted aortic arch
- Kawasaki
- Long QT
- LV non-compaction
- LVOTO
- MR
- MS
- MV Prolapse
- PA
- PAPVR
- PDA
- PFO
- PR
- PS
- RVOTO
- TA
- TAPVR
- TGA-D
- TGA-L
- TOF
- TR
- Truncus
- VSD
- Suprventricular arrhythmia
- Ventricular arrhythmia
- Bradyarrhythmia
- Other

Total Number of Surgeries

- 0
- 1
- 2
- 3
- 4
- 5
- More than 5

Name of First Surgery

- ASD closure
- ASO
- AVC repair
- Coarc repair
- Fontan
- Glenn
- Mustard/Senning
- MVR
- Pacemaker
- PDA closure
- PFO closure
- PVR
- RVOT/LVOT conduit replacement
- Shunt
- Truncus repair
- TVR
- VSD closure
- Other

Age at First Surgery (years, include partial)

Name of Second Surgery

- ASD closure
- ASO
- AVC repair
- Coarc repair
- Fontan
- Glenn
- Mustard/Senning
- MVR
- Pacemaker
- PDA closure
- PFO closure
- PVR
- RVOT/LVOT conduit replacement
- Shunt
- Truncus repair
- TVR
- VSD closure
- Other

Age at Second Surgery (years, include partial)

Name of Third Surgery

- ASD closure
- ASO
- AVC repair
- Coarc repair
- Fontan
- Glenn
- Mustard/Senning
- MVR
- Pacemaker
- PDA closure
- PFO closure
- PVR
- RVOT/LVOT conduit replacement
- Shunt
- Truncus repair
- TVR
- VSD closure
- Other

Age at Third Surgery (years, include partial)

Name of Fourth Surgery

- ASD closure
- ASO
- AVC repair
- Coarc repair
- Fontan
- Glenn
- Mustard/Senning
- MVR
- Pacemaker
- PDA closure
- PFO closure
- PVR
- RVOT/LVOT conduit replacement
- Shunt
- Truncus repair
- TVR
- VSD closure
- Other

Age at Fourth Surgery (years, include partial if less than 1, round to nearest integer)

Name of Fifth Surgery

- ASD closure
- ASO
- AVC repair
- Coarc repair
- Fontan
- Glenn
- Mustard/Senning
- MVR
- Pacemaker
- PDA closure
- PFO closure
- PVR
- RVOT/LVOT conduit replacement
- Shunt
- Truncus repair
- TVR
- VSD closure
- Other

Age at Fifth Surgery (years, include partial if less than 1, round to nearest integer)

Developmental Delay?

- Yes
- No

Type Developmental Delay

- Down Syndrome
- Williams Syndrome
- Noonan Syndrome
- DiGeorge Syndrome
- CHARGE Syndrome
- Jacobsen Syndrome
- Turner Syndrome
- Alagille Syndrome
- VACTERL Syndrome
- Other

english-speaking

- Yes
- No

Further description for any "other" defects/surgeries/DD or to describe persons with >5 surgeries

PHQ-9 Total Score

(See notes on alert levels)

PHQ-9 Total Score Manual Calculation

(Calculate manually if missing any response.)

Incentivescontact

Gift Card

- Walmart
- Amazon
- Starbucks

Parking

- Deck
- Valet

Date gift card #1:

E-mail Reminder 1

E-mail Reminder 2

E-mail Reminder 3

Phone Reminder 1

Phone Reminder 2

Phone Reminder 3

Notes

Date gift card #2:

E-mail Reminder 1- HRU

E-mail Reminder 2-HRU

E-mail Reminder 3-HRU

E-mail Reminder 4-HRU

E-mail Reminder 5-HRU

E-mail Reminder 6-HRU

Phone Reminder 1-HRU

Phone Reminder 2-HRU

Phone Reminder 3-HRU

Phone Reminder 4-HRU

Phone Reminder 5-HRU

Phone Reminder 6-HRU

Notes:

ACHD_CHOI

Please complete the survey below.

Thank you!

Thank you for taking part in this study! Please answer the following questions. All your answers are confidential .

- 53) Gender
 - Female
 - Male
- 54) Ethnicity
 - Hispanic or Latino
 - NOT Hispanic or Latino
- 55) Race
 - American Indian/Alaska Native
 - Asian
 - Native Hawaiian or Other Pacific Islander
 - Black or African American
 - White
 - More Than One Race
- 56) What is your marital status?
 - Single
 - Married
 - Living with Partner
 - Divorced or separated
 - Widowed
- 57) Who do you live with? (Check all that apply)
 - Alone
 - With spouse
 - With parent(s)
 - With children
 - With siblings
 - With friends
- 58) What type of health insurance do you have?
 - Private Insurance
 - Medicaid or Medicare
 - Uninsured
- 59) What is your highest level of education?
 - Less than high school
 - High school
 - College degree
 - Graduate degree
- 60) What is your job status?
 - Employed full-time
 - Employed part-time
 - Homemaker
 - Student
 - Unemployed
 - On Disability
- 61) Who helps you the most in managing your heart condition?
 - Parent
 - Spouse or Partner
 - Sibling
 - Other Family Member
 - Friend
- 62) How does this person help you manage you heart condition? (Check all that apply)
 - Making doctor's appointments
 - Transportation to appointments
 - Getting my medications
 - Reminding me to take medications
 - Deciding if I need to see the doctor
 - Making decisions about my medical care
 - Encouraging me to stay healthy (exercise, healthy diet, stop smoking, or limit alcohol)
 - Providing me with support when I am sad or anxious about my heart condition
- 63) How much help do you RECEIVE from your family to manage your heart condition? Tap on the white bar to move the blue box.

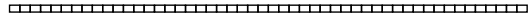
No help. I do everything.

Help with everything

64) How much help to you WANT to receive from your family to manage your heart condition? Tap on the white bar to move the blue box.

I do not want any help

I want help with everything



(Place a mark on the scale above)

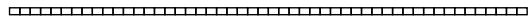
65) How many friends do you have with a congenital heart defect?

- 0
- 1
- 2
- 3
- 4
- 5 or more

Please answer the following questions.

66) How satisfied are you with the overall quality of your life? Tap on the white bar to move to blue square.

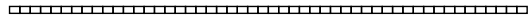
Not at all satisfied Completely satisfied



(Place a mark on the scale above)

67) Compared to people your own age, how would you rate your quality of life? Tap on the white bar to move to blue square.

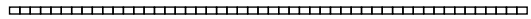
Much worse Much better



(Place a mark on the scale above)

68) How satisfied are you with your current health? Tap on the white bar to move to blue square.

Not at all satisfied Completely satisfied



(Place a mark on the scale above)

Please respond to each question or statement by marking one answer per row.

	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
69) Are you able to do chores such as vacuuming or yard work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
70) Are you able to go up and down stairs at a normal pace?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
71) Are you able to go for a walk of at least 15 minutes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
72) Are you able to run errands and shop?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please respond to each question or statement by marking one answer per row .

	Never	Rarely	Sometimes	Often	Always
73) In the past 7 days, I felt fearful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
74) In the past 7 days, I found it hard to focus on anything other than my anxiety.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
75) In the past 7 days, my worries overwhelmed me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
76) In the past 7 days, I felt uneasy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please respond to each question or statement by marking one answer per row .

	Never	Rarely	Sometimes	Often	Always
77) During the past 7 days, I felt worthless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
78) During the past 7 days, I felt helpless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
79) During the past 7 days, I felt depressed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80) During the past 7 days, I felt hopeless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please respond to each question or statement by marking one answer per row .

- | | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 81) During the past 7 days, I feel fatigued. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 82) During the past 7 days, I have trouble starting things because I am tired. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 83) In the past 7 days, how run-down did you feel on average? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 84) In the past 7 days, how fatigued were you on average? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please respond to each question or statement by marking one answer per row .

- | | | | | | |
|--|-------------------------------------|---------------------------------------|-----------------------------------|--------------------------------------|------------------------------------|
| 85) In the past 7 days, my sleep quality was..... | Very poor
<input type="radio"/> | Poor
<input type="radio"/> | Fair
<input type="radio"/> | Good
<input type="radio"/> | Very good
<input type="radio"/> |
| 86) In the past 7 days, my sleep was refreshing. | Not at all
<input type="radio"/> | A little bit
<input type="radio"/> | Somewhat
<input type="radio"/> | Quite a bit
<input type="radio"/> | Very much
<input type="radio"/> |
| 87) In the past 7 days, I had a problem with my sleep. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 88) In the past 7 days, I had difficulty falling asleep. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please respond to each question or statement by marking one answer per row .

- | | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 89) In the past 7 days, I am satisfied with how much work I can do (include work at home). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 90) In the past 7 days, I am satisfied with my ability to work (include work at home). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 91) In the past 7 days, I am satisfied with my ability to do regular personal and household responsibilities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 92) In the past 7 days, I am satisfied with my ability to perform my daily routines. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please respond to each question or statement by marking one answer per row.

- | | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 93) In the past 7 days, how much did pain interfere with your day to day activities? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 94) In the past 7 days, how much did pain interfere with work around the home? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 95) In the past 7 days, how much did pain interfere with your ability to participate in social activities? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 96) In the past 7 days, how much did pain interfere with your household chores? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

- 97) In the past 7 days, how would you rate your pain on average?

- 0=no pain
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10=worst pain imaginable

Self-care

Please complete the survey below.

Thank you!

Thank you for taking part in this study! You are about to take several surveys. Your answers are confidential. It will probably take you between 1 to 2 hours to complete the surveys. You can take breaks as often as you need.

Please contact Nancy McCabe at 404-234-1574 or nmccabe@emory.edu if you have any questions .

What is the name of your heart defect?

How many heart surgeries have you had?

- 0
 1
 2
 3
 4
 5
 More than 5

List all of the heart surgeries you have had

Do you have any medical conditions other than your heart defect?

- Yes
 No

List your other medical conditions.

Please list your current medications and dosages.

What is your current exercise recommendation?
(Check all that apply)

- No restrictions
 Avoid contact sports (such as football or hockey).
 Gentle exercise only (such as walking).
 Avoid competitive sports
 Avoid heavy lifting (weight that makes you strain or get red in the face).

Check all special precautions that apply to you.

- Flu shot recommended
 Avoid metal detectors
 Supplemental oxygen for air travel recommended
 Avoid traveling to high elevations (>5,000 feet)
 Take antibiotics prior to dental procedures
 Notify my providers to take blood pressure in only one arm. My pressure is lower in one arm than in the other because of a prior surgery.
 Eat a low-salt diet (< 2,000 mg per day)
 Always use air filters when getting IV fluids or medications

Do you have an advance directive?

- Yes
 No
 I do not know

Are you a woman?

- Yes
 No

What is your current pregnancy recommendation?

- Pregnancy not currently recommended because of risk to me and my baby.
 Consultation with my heart doctor prior to becoming pregnant.
 Planned pregnancy under direct supervision of my heart doctor.
 No restrictions. My risk is the same as for women without a heart defect.

What is your current contraception recommendation?

- Progestin only
- Low dose estrogen/progestin
- Barrier method (such as condoms or diaphragms)
- IUD (such as paraguard, marina)
- No special recommendations. My risks are the same as a women without a heart defect.
- Not applicable (hysterectomy, tubal ligation, or menopause)

For each of the following questions, please choose the number that corresponds to your confidence at the present time .

	not confident at all 1	2	3	4	5	6	7	8	9	totally confident 10
How confident are you that you can get family to help you with the things you need (such as household chores like shopping, cooking, or transport)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How confident are you that you can get emotional support from family (such as listening or talking over your problems)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How confident are you that you can get emotional support from resources other than family, if needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How confident are you that you can get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than family if needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please answer the following questions.

Do you currently take medications?

- Yes
- No

Are you a woman and physically able to have children?

- Yes
- No

Think about how you have been feeling in the last month as you complete these questions.

Listed below are common instructions given to people with congenital heart defects.

How often do you do the following?

	Never	Sometimes	Frequently	Always or daily
Keep your heart doctor appointments?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use tobacco products (cigarettes, chew, snuff)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drink more than 3 alcoholic beverages per week?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Try to maintain a health weight?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make healthy food choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Call your heart doctor before having minor surgeries or procedures?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take care of your teeth (brushing, going to the dentist)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Exercise at least 3 days per week?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get 7-8 hours of sleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take some time to relax each day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spend time with close friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take medications as prescribed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use a system, such as a pillbox, to help you remember your medications?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Forget to take a medication?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use birth control?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make a plan with your heart doctor before becoming pregnant?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

People with congenital heart defects may have changes in the way they feel or notice that their heart is causing health problems. How often do you:

	Never or rarely	Sometimes	Frequently	Always or daily
Check you ankles for swelling?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attribute being more tired than usual on your heart?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Watch for changes in the way you feel?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Experience side effects of medication?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Watch for heart symptoms when you have the flu or other illness?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feel if your heart beats too fast or too slow?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

People with congenital heart defects sometimes experience symptoms. Have you had any symptoms related to your heart defect in the past MONTH?
[Common symptoms include irregular heart beats, chest pain, passing out, shortness of breath, sudden weakness, tired doing usual activities, blueness of nailbeds or lips, or abdominal or ankle swelling]

- Yes
- No

How likely were you to try one of these actions to relieve your symptoms?

	Not likely	Somewhat likely	Likely	Very likely
Change your activity level (slow down, rest).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Call your doctor or nurse for guidance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Take an extra medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How confident are you that you can:

	Not confident	Somewhat confident	Very confident	Extremely confident
Keep yourself free of symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow the treatment advice you have been given?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognize changes in your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Evaluate the importance of your symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do something that will relieve your symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Evaluate how well an action works to relieve your symptoms?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please answer the following questions.

In the past month, have you experienced shortness of breath performing your usual activities?

- Yes
 No

How FREQUENTLY did you experience shortness of breath performing your usual activities?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How SEVERE was the shortness of breath performing your usual activities?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the shortness of breath performing your usual activities affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you experienced shortness of breath at rest?

- Yes
 No

How frequently did you experience shortness of breath at rest?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was shortness of breath at rest?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did having shortness of breath at rest affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you experienced shortness of breath that wakes you up at night?

- Yes
 No

How frequently did you experience shortness of breath that wakes you up at night?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the shortness of breath that wakes you up at night?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the shortness of breath that wakes you up at night affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you experienced difficulty climbing stairs or walking your usual distance?

- Yes
- No

How frequently did you experience difficulty climbing stairs or walking your usual distance?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was difficulty climbing stairs or walking your usual distance?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the difficulty climbing stairs or walking your usual distance affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you been unable to complete daily chores or activities?

- Yes
- No

How frequently were you unable to complete daily chores or activities?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the inability to complete daily chores or activities?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the inability to complete daily chores or activities affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you felt tired or a lack of energy?

- Yes
- No

How frequently did you feel tired or a lack of energy?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was your tiredness?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did being tired affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you had swelling in your feet, ankles, or abdomen?

- Yes
 No

How frequently did you experience swelling in your feet, ankles, or abdomen?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the swelling in your feet, ankles, or abdomen?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the swelling in your feet, ankles, or abdomen affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you had excessive sweating?

- Yes
 No

How frequently did you experience the excessive sweating?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the excessive sweating?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the excessive sweating affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you had chest pressure or chest pain?

- Yes
 No

How frequently did you experience chest pressure or chest pain?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the chest pressure or chest pain?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the chest pressure or chest pain affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you had fluttering in your chest (palpitations or racing heart)?

- Yes
- No

How frequently did you experience fluttering in your chest (palpitations or racing heart)?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the fluttering in your chest (palpitations or racing heart)?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the fluttering in your chest (palpitations or racing heart) affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you had difficulty sleeping?

- Yes
- No

How frequently did you experience difficulty sleeping?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the difficulty sleeping?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the difficulty sleeping affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you had difficulty concentrating or forgetfulness?

- Yes
- No

How frequently did you experience difficulty concentrating or forgetfulness?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the difficulty concentrating or forgetfulness?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did difficulty concentrating or forgetfulness affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you had bleeding due to blood thinners?

- Yes
 No

How frequently did you experience bleeding due to blood thinners?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the bleeding due to blood thinners?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the bleeding due to blood thinners affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you had a headache?

- Yes
 No

How frequently did you experience a headache?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the headache?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the headache affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you had dizziness or lightheadedness?

- Yes
 No

How frequently did you experience dizziness or lightheadedness?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the dizziness or lightheadedness?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the dizziness or lightheadedness affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you experience fainting or passing out?

- Yes
 No

How frequently did you experience fainting or passing out?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the fainting or passing out?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the fainting or passing out affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you had purple/blueness of nailbeds or lips?

- Yes
 No

How frequently did you experience purple/blueness of nailbeds or lips?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the purple/blueness of nailbeds or lips?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the purple/blueness of nailbeds or lips affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you had abdominal pain or discomfort?

- Yes
 No

How frequently did you experience abdominal pain or discomfort?

- Rarely
 A few days
 Half the days
 Most days
 Everyday

How severe was the abdominal pain or discomfort?

- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe

How much did the abdominal pain or discomfort affect your enjoyment of life?

- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

-
-
- In the past month, have you had muscle cramps?
- Yes
 No
- How frequently did you experience muscle cramps?
- Rarely
 A few days
 Half the days
 Most days
 Everyday
- How severe were the muscle cramps?
- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe
- How much did the muscle cramps affect your enjoyment of life?
- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal
- In the past month, have you felt irritable?
- Yes
 No
- How frequently did you experience irritability?
- Rarely
 A few days
 Half the days
 Most days
 Everyday
- How severe was the irritability?
- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe
- How much did the irritability affect your enjoyment of life?
- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal
- In the past month, have you felt worried?
- Yes
 No
- How frequently did you experience worry?
- Rarely
 A few days
 Half the days
 Most days
 Everyday
- How severe was the worry?
- Not Severe At All
 A Little Severe
 Somewhat Severe
 Moderately Severe
 Very Severe
- How much did the worrying affect your enjoyment of life?
- Not At All
 A Little Bit
 Somewhat
 A Lot
 A Great Deal

In the past month, have you felt sad?

- Yes
- No

How frequently did you experience sadness?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the sadness?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the sadness affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

In the past month, have you had a lack of interest or problems with sexual functioning?

- Yes
- No

How frequently did you experience a lack of interest or problems with sexual functioning?

- Rarely
- A few days
- Half the days
- Most days
- Everyday

How severe was the lack of interest or problems with sexual functioning?

- Not Severe At All
- A Little Severe
- Somewhat Severe
- Moderately Severe
- Very Severe

How much did the lack of interest or problems with sexual functioning affect your enjoyment of life?

- Not At All
- A Little Bit
- Somewhat
- A Lot
- A Great Deal

Over the last 2 WEEKS, how often have you been bothered by any of the following problems?

- | | |
|--|---|
| 1. Little interest or pleasure in doing things | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 2. Feeling down, depressed, or hopeless | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 3. Trouble falling or staying asleep or sleeping too much | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 4. Feeling tired or having little energy | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 5. Poor appetite or overeating | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 6. Feeling bad about yourself? | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 7. Trouble concentrating on things ? | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 8. Moving or speaking so slowly that other people could have noticed | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |
| 9. Thoughts that you would be better off dead or of hurting yourself in some way | <input type="radio"/> Not at all
<input type="radio"/> Several days
<input type="radio"/> More than half the days
<input type="radio"/> Nearly every day |

This questionnaire lists various attitudes and behaviors of parents. As you remember your mother (or primary caregiver) in your first 16 years of life, place a check in the most appropriate box next to each question.

	Very like	Moderately like	Moderately unlike	Very unlike
Spoke to me in a warm and friendly voice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not help me as much as I needed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me do those things I like doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seemed emotionally cold to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Appeared to understand my problems and worries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was affectionate to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Liked me to make my own decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not want me to grow up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to control everything I did	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Invaded my privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enjoyed talking things over with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Frequently smiled at me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

This questionnaire lists various attitudes and behaviors of parents. As you remember your mother (or primary caregiver) in your first 16 years of life, place a check in the most appropriate box next to each question.

Tended to baby me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not seem to understand what I needed or wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me decide things for myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made me feel I wasn't wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Could make me feel better when I was upset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not talk with me very much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tried to make me feel dependent on her/him	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Felt I could not look after myself unless she/he was around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gave me as much freedom as I wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me go out as often as I wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was overprotective of me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did not praise me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Let me dress in any way I pleased	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Health Resource Use 1

Please complete the survey below.

Thank you!

Please answer the following questions.

In the past month, how many times did you visit a doctor?

- 0
- 1
- 2
- 3
- 4
- 5

At your FIRST visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your SECOND visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your THIRD visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FOURTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FIFTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

In the past month, how many times did you go to the emergency room?

- 0
- 1
- 2
- 3

At your FIRST emergency room visit, did you go to the Emory emergency room?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

At your SECOND emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

At your THIRD emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

In the past month, how many times were you hospitalized?

- 0
- 1
- 2
- 3

At your FIRST hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

At your SECOND hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

At your THIRD hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

Health Resource Use 2

Please complete the survey below.

Thank you!

In the past month, how many times did you visit a doctor?

- 0
- 1
- 2
- 3
- 4
- 5

At your FIRST visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your SECOND visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your THIRD visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FOURTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FIFTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

In the past month, how many times did you go to the emergency room?

- 0
- 1
- 2
- 3

At your FIRST emergency room visit, did you go to the Emory emergency room?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

At your SECOND emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

At your THIRD emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

In the past month, how many times were you hospitalized?

- 0
- 1
- 2
- 3

At your FIRST hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

At your SECOND hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

At your THIRD hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

Health Resource Use 3

Please complete the survey below.

Thank you!

In the past month, how many times did you visit a doctor?

- 0
- 1
- 2
- 3
- 4
- 5

At your FIRST visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your SECOND visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your THIRD visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FOURTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

At your FIFTH visit, what kind of doctor did you see?

- Primary Care Provider
- Psychologist or Counselor
- Heart Doctor
- Pacemaker Doctor
- Lung Doctor
- Liver Doctor
- Kidney Doctor
- Diabetes Doctor
- Surgery Doctor
- Other

Was this doctor's appointment at Emory?

- Yes
- No

What was the reason you had to go to the doctor?

In the past month, how many times did you go to the emergency room?

- 0
- 1
- 2
- 3

At your FIRST emergency room visit, did you go to the Emory emergency room?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

At your SECOND emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

At your THIRD emergency room visit, did you go to the Emergency Room at Emory?

- Yes
- No

What was the reason you had to go to the emergency room?

List any tests or procedures you had done in the Emergency Room

In the past month, how many times were you hospitalized?

- 0
- 1
- 2
- 3

At your FIRST hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

At your SECOND hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

At your THIRD hospitalization, did you go to Emory?

- Yes
- No

How many days were you in the hospital?

What was the reason you were hospitalized?

List any tests or procedures you had done in the hospital.

HRU Validation

HRU Notes: _____

Date of Recruitment _____

Number of doctor visits. _____

Number of cardiology doctor visits. _____

Number of non-cardiology doctor visits. _____

Number of routine doctor visits. _____

Number of non-routine doctor visits. _____

- Types of doctors
- Primary Care Provider
 - Psychologist or Counselor
 - Heart Doctor
 - Pacemaker Doctor
 - Lung Doctor
 - Liver Doctor
 - Kidney Doctor
 - Diabetes Doctor
 - Surgery Doctor
 - Other

Number of emergency room visits _____

Reasons for ED visit _____

Number of heart-related ED visits _____

Number of non-heart related ED visit _____

Number of hospitalizations _____

Days in hospital _____

Reason for hospitalizations _____

Number of heart related hospitalizations _____

Number of non-heart related hospitalizations _____

Charlson Comorbidity Index

Comorbidity (Choose all that are present) Assigned weights for each condition the patient has ()

- Myocardial infarct (+1)
- Congestive heart failure (+1)
- Peripheral vascular disease (+1)
- Cerebrovascular disease (except hemiplegia) (+1)
- Dementia (+1)
- Chronic pulmonary disease (+1)
- Connective tissue disease (+1)
- Ulcer disease (+1)
- Mild liver disease (+1)
- Diabetes (without complications) (+1)
- Diabetes with end organ damage (+2)
- Hemiplegia (+2)
- Moderate or severe renal disease (+2)
- Solid tumor (non metastatic) (+2)
- Leukemia (+2)
- Lymphoma, Multiple myeloma (+2)
- Moderate or severe liver disease (+3)
- Metastatic solid tumor (+6)
- AIDS (+6)

Age

- 50 - 59 (+1)
- 60 - 69 (+2)
- 70 - 79 (+3)
- 80 - 89 (+4)
- 90 - 99 (+5)

List actual comorbidities (may want to use descriptively)

Total points:

New Comorbidity Score

Comorbidity Notes

List actual comorbidities (may want to use descriptively)

Comorbidity (Choose all that are present)

-
-
- Myocardial infarct
 - Congestive heart failure
 - Peripheral vascular disease
 - Cerebrovascular disease (except hemiplegia)
 - Dementia
 - PAH
 - Connective tissue disease
 - Ulcer disease
 - Mild liver disease
 - Diabetes (without complications)
 - Diabetes with end organ damage
 - Hemiplegia
 - Moderate or severe renal disease
 - Solid tumor (non metastatic)
 - Leukemia
 - Lymphoma, Multiple myeloma
 - Moderate or severe liver disease
 - Metastatic solid tumor
 - AIDS
 - Arrhythmia
 - Thyroid Disease
 - GERD/Gastritis
 - Anxiety
 - Depression
 - Other mental illness (bipolar, personality disorder, etc)
 - Musculoskeletal disorder
 - Anemia
 - OSA
 - Asthma
 - COPD
 - Dyslipidemia
 - Hypertension
 - Cholelithiasis
 - Gout
 - Other

Vital Signs

Date of Vital Signs	_____
Height (cm)	_____
Weight (kilograms)	_____
BMI	_____
Systolic BP	_____
Diastolic BP	_____
Heart Rate	_____
Oxygen Saturation	_____
NYHA Class	<input type="radio"/> I <input type="radio"/> II <input type="radio"/> III <input type="radio"/> IV

Sc Validation Items

Annual flu shot 2013-2104

- Yes
- No

Number of Cardiology office visits in past year.

Number of hospitalizations in past year.

Number of ED visits in past year.

Medication List

Please indicate all other medications by generic name, dose and frequency.

Medication 1 _____

Medication 1 dose _____

- Medication 1 unit
- g
 - mg
 - mcg
 - mL
 - drops/puffs
 - units
 - other

- Medation 1 frequency
- qd
 - bid
 - tid
 - qid
 - q4-6 hrs
 - prn
 - Unknown

- Class of Drug
- ACE Inhibitor
 - ARB
 - Beta-blocker
 - Anti-arrhythmic
 - Hydralazine
 - Nitrate
 - Diuretic
 - Anticoagulant
 - Pulmonary vasodilator
 - Anti-anxiety
 - Lipid-lowering
 - Analgesic
 - NSAID
 - Herbal supplement
 - Other

Medication 2 _____

Medication 2 dose _____

- Medication 2 unit
- g
 - mg
 - mcg
 - mL
 - drops/puffs
 - units
 - other

- Medation 2 frequency
- qd
 - bid
 - tid
 - qid
 - q4-6 hrs
 - prn
 - Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 3

Medication 3 dose

Medication 3 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 3 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 4

Medication 4 dose

Medication 4 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 4 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 5

Medication 5 dose

Medication 5 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 5 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 6

Medication 6 dose

Medication 6 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 6 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 7

Medication 7 dose

Medication 7 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 7 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 8

Medication 8 dose

Medication 8 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 8 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 9

Medication 9 dose

Medication 9 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 9 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 10

Medication 10 dose

Medication 10 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 10 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 11

Medication 11 dose

Medication 11 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 11 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 12

Medication 12 dose

Medication 12 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 12 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 13

Medication 13 dose

Medication 13 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 13 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 14

Medication 14 dose

Medication 14 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 14 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 15

Medication 15 dose

Medication 15 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 15 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 16

Medication 16 dose

Medication 16 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 16 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 17

Medication 17 dose

Medication 17 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 17 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 18

Medication 18 dose

Medication 18 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 18 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Medication 19

Medication 19 dose

Medication 19 unit

- g
- mg
- mcg
- mL
- drops/puffs
- units
- other

Medation 19 frequency

- qd
- bid
- tid
- qid
- q4-6 hrs
- prn
- Unknown

Class of Drug

- ACE Inhibitor
- ARB
- Beta-blocker
- Anti-arrhythmic
- Hydralazine
- Nitrate
- Diuretic
- Anticoagulant
- Pulmonary vasodilator
- Anti-anxiety
- Lipid-lowering
- Analgesic
- NSAID
- Herbal supplement
- Other

Total # daily meds

Labs

Systemic Ventricle

- Left
- Right

Systemic Ventricular Dysfunction

- none
- mild
- moderate
- severe

Ejection Fraction

K

Na

Cl

CO2

Glucose

BUN

Cr

Albumin

Ca

WBC

Hgb

Hct

Six Minute Walk Test

6-Minute Walk Test Date _____

Reasons for Test NOT Performed

- Test was done
- Patient Declined
- Disability (mental, physical)
- Medical (illness, gout, chest pain, etc)
- Technical

Did the patient use oxygen during the 6MWT?

- Yes
- No

Resting Vital Signs

Systolic BP: _____

Diastolic BP: _____

HR: _____

RR: _____

SpO2 (%) _____

BORG Scale-Baseline

- No effort
- very very light
- 8
- very light
- 10
- fairly light
- 12
- somewhat hard
- 14
- hard
- 16
- very hard
- 18
- very very hard
- maximum

The Test

Time Started: _____

Time Stopped: _____

Total Time Walked (minutes) _____

Total distance walked in feet: _____

Total distance walked (meters) _____

Did participant stop during 6MWT?

- No
- Yes

Stop Duration _____
(minutes)

Symptoms during 6MWT:

- Chest Pain
- Syncope
- Lightheadedness
- Staggering
- Muscle Fatigue
- Intolerable Dyspnea
- Leg Cramps
- Pale/ashen appearance
- Diaphoresis
- None

Highest HR

Lowest SpO2 (%)

Post Vital Signs

Systolic BP:

Diastolic BP:

HR:

RR:

SpO2 (%)

BORG Scale-Maximal

- No effort
- very very light
- 8
- very light
- 10
- fairly light
- 12
- somewhat hard
- 14
- hard
- 16
- very hard
- 18
- very very hard
- maximum

2 Min Post Vital Signs

Systolic BP:

Diastolic BP:

HR:

RR:

SpO2 (%)

Six minutes walk test notes

Gad7

Please complete the survey below.

Thank you!

Over the LAST 2 WEEKS, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
570) Feeling nervous, anxious or on edge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
571) Not being able to stop or control worrying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
572) Worrying too much about different things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
573) Trouble relaxing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
574) Being so restless that it is hard to sit still	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
575) Becoming easily annoyed or irritable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
576) Feeling afraid as if something awful might happen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Knowledge Validation

What is the name of your heart defect?

Points_Name

- incorrect
- partially correct
- correct

How many heart surgeries have you had?

- 0
- 1
- 2
- 3
- 4
- 5
- More than 5

Points_Name

- incorrect
- partially correct
- correct

List all of the heart surgeries you have had

Points_Name

- incorrect
- partially correct
- correct

Do you have any medical conditions other than your heart defect?

- Yes
- No

Points_Name

- incorrect
- partially correct
- correct

List your other medical conditions.

Points_Name

- incorrect
- partially correct
- correct

Please list your current medications and dosages.

Points_Name

- incorrect
- partially correct
- correct

What is your current exercise recommendation?
(Check all that apply)

- No restrictions
- Avoid contact sports (such as football or hockey).
- Gentle exercise only (such as walking).
- Avoid competitive sports
- Avoid heavy lifting (weight that makes you strain or get red in the face).

Points_Name

- incorrect
- partially correct
- correct

Check all special precautions that apply to you.

- Flu shot recommended
- Avoid metal detectors
- Supplemental oxygen for air travel recommended
- Avoid traveling to high elevations (>5,000 feet)
- Take antibiotics prior to dental procedures
- Notify my providers to take blood pressure in only one arm. My pressure is lower in one arm than in the other because of a prior surgery.
- Eat a low-salt diet (< 2,000 mg per day)
- Always use air filters when getting IV fluids or medications

Points_Name

- incorrect
- partially correct
- correct

Do you have an advance directive?

- Yes
- No

Points_Name

- incorrect
- partially correct
- correct

Are you a woman?

- Yes
- No

What is your current pregnancy recommendation?

- Pregnancy not currently recommended because of risk to me and my baby.
- Consultation with my heart doctor prior to becoming pregnant.
- Planned pregnancy under direct supervision of my heart doctor.
- No restrictions. My risk is the same as for women without a heart defect.

Points_Name

- incorrect
- partially correct
- correct

What is your current contraception recommendation?

- Progestin only
- Low dose estrogen/progestin
- Barrier method (such as condoms or diaphragms)
- IUD (such as paraguard, marina)
- No special recommendations. My risks are the same as a women without a heart defect.
- Not applicable (hysterectomy, tubal ligation, or menopause)

Points_Name

- incorrect
- partially correct
- correct

Notes:

Total Score

Knowledge Score

Yes/No refers to whether or not the subject answered the question CORRECTLY. Yes, answered correctly. No, did not answer correctly.

- Name_CHD Yes
 No
- No. Surgeries Yes
 No
- Name Surgeries Yes
 No
- Other Conditions Yes
 No
- Name Other Conditions Yes
 No
- Medications Yes
 No
- Exercise: No restrictions Yes
 No
- Exercise: no contact sports Yes
 No
- Exercise: Gentle only Yes
 No
- Exercise: no competitive sports Yes
 No
- Exercise: No heavy lifting Yes
 No
- Special Precautions (SP): flu shot Yes
 No
- SP: no metal detectors Yes
 No
- SP: travel with oxygen Yes
 No
- SP: avoid high elevation Yes
 No
- SP: antibiotics prior to dental Yes
 No
- SP: BP one arm Yes
 No
- SP: low salt diet Yes
 No
- SP: air filters on IV lines Yes
 No

Advance Directives

- Yes
- No

Pregnancy Recommendation

- Yes
- No

Contraception Recommendation

- Yes
- No

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Table 2.4. Literature Synthesis Supplemental Table

Study	N	Mean Age	ACHD Type or Severity	Adequacy	Antecedents	Outcomes
Physical Activity						
van der Borm et al (2015)	40	36	TGA	58% participated in regular physical activity	Patients participating in sports were more likely to be L-TGA vs D-TGA. No differences in age, gender, BMI, NYHA Class, presence of pacemaker, or medications	Participation in regular physical activity was associated with higher peak oxygen uptake, decreased pro-BNP levels, and lower incidence of clinical events.
Overgaard et al (2014)	59	24	Single Ventricle	39% with no physical activity	NR	NR
Buys et al (2014)	73	27	TOF	55% with no physical activity	BMI (r=.26) Perceived physical functioning (r=.27)	Moderate relationship between physical activity levels and peak oxygen uptake (r=.23)
Ubeda-Tikkanen et al (2013)	145	34	TOF 36% Fontan 10% Systemic RV 23% Other 31%	42% with low levels of physical activity	BMI, systolic BP, resting HR, being on a beta blocker-differences in baseline physical activity levels	Increasing physical activity levels from <2 times per week to ≥2 times per week significantly improved exercise capacity
Buys et al (2013)	103	29	Aortic Coarctation	50% with no physical activity	NR	Significant relationship with exercise capacity (peak oxygen uptake, r=.21-.35) and QOL (.20-.28)
Westhoff-Bleck et al (2013)	48	29	TGA (Mustard repair)	n/a	NR	Increased peak oxygen uptake, exercise time and load, and reduced symptoms; no affect on QOL

Study	N	Mean Age	ACHD Type or Severity	Adequacy	Antecedents	Outcomes
Cordina et al (2013)	11	32	Fontan	n/a	NR	Resistance training improves exercise capacity (peak oxygen uptake) and hemodynamic parameters
Becker-Grunig (2013)	20	NR	PAH	n/a	NR	Exercise training improves exercise capacity (peak oxygen uptake and maximal workload) and QOL.
Muller et al (2012)	330	18-61	TGATOF/ Fontan/Other	24% did not meet physical activity recommendations	Not related to type of heart defect after adjusting for age; men had higher rates of daily activity; daily activity decreased with age	Moderate relationship between daily activity and exercise capacity ($r=.44$), but not QOL ($r=.03$)
Dua et al (2010)	61	32	42% simple 32% moderate 26% severe	n/a	Gender differences	A simple, home-based 10 week walking program improved quality of life, physical activity levels, and treadmill test duration in all severities of CHD
Winter et al (2008)	47	35	66% D-TGA (Mustard/Senning) 34% L-TGA	64% had physical activity levels below population norms	Not related to ejection fraction or BNP level or mental functioning.	Moderate relationship between daily activity and exercise capacity (peak oxygen uptake) ($r=.40$), and physical QOL ($r=.41$)

Study	N	Mean Age	ACHD Type or Severity	Adequacy	Antecedents	Outcomes
De Belser et al (2007)	70	24	D-TGA (Mustard/Senning)	Majority had physical activity levels comparative to normative controls except for less involvement in sports-related activities	Physical activity levels decreased with age (r= .38)	NR
Dua et al (2007)	61	32	30% Simple	77%, 84%, and 100% in NYHA Class I/II/III respectively, did not meet physical activity recommendations	Lower physical activity with higher NYHA Class	NR
Routine Follow-Up						
Wray et al (2013)	216	32	TOF	24% of patients were not in specialty care	Lack of knowledge of specialty care availability	48% of late deaths occurred in persons not in specialty care, no persons lost to follow-up had replacement of pulmonary valve
Norris et al (2013)	153	21-27	56% Moderate 44% Severe	18% of adults were lost to follow-up; 69% of adults still followed by pediatric cardiologists	NR	NR

Study	N	Mean Age	ACHD Type or Severity	Adequacy	Antecedents	Outcomes
Gurvitz et al (2013)	922	20	27% Simple 51% Moderate 23% Severe	42% of patients had a gap in care between pediatric and adult care of more than 3 years; 8% had a gap >10 years	Feeling well, lack of knowledge of follow-up needs, and complete absence of medical care most commonly self-reported reasons for gaps in care. Disease complexity and clinic location significantly predicted gaps in care, but not gender, race, or education level.	NR
Goossens et al (2011)	794	18-22	Simple 34%, Moderate 57%, Severe 9%	7% of patients lost to follow-up, 10% of patients not receiving appropriate level of care	Male sex, no prior heart surgery and greater CHD complexity associated with inappropriate follow-up, but not with prior catheter intervention or distance lived from hospital	NR
Vis et al (2011)	593	40	85% Simple 14% Moderate 1% Severe	100% of adults in study were lost to follow-up	NR	16% of patients returning to care had 76 new cardiac findings
Mackie et al (2009)	643	22	61% Simple 26% Other 13% Severe	61% of children born in 1983 were lost to follow-up care.	Male sex, non-severe CHD, history of follow-up outside of an academic healthcare system more likely to be lost to follow-up	NR

Study	N	Mean Age	ACHD Type or Severity	Adequacy	Antecedents	Outcomes
Yeung et al (2008)	158	NR	All moderate or complex, primary diagnosis TOF (30%)	63% of adults with a median duration of lapse in care of 10 years (2-50 years)	Lapse in care greater than 3 years associated with older age, living independently from parents, having a moderate versus complex CHD	Lapses in care greater than 3 years associated with 5 times the odds of being symptomatic at presentation, 12 times more likely to have a new diagnosis, and 3 times more likely to need an urgent intervention
Substance Use						
Zomer et al (2012)	1496	39	46% Simple 44% Moderate 10% Severe	50% less likely to smoke tobacco than general population, NS 10% less likely to use alcohol, 50% less have lifetime soft drug use	No differences by gender; significant differences by CHD severity	NR
Reid et al (2008)	197	19-20	All moderate or severe CHD	20% regular smokers, 81% used alcohol in past 30 days and 44% binge drinking during same period; 41% have used marijuana and 22% illicit drugs in lifetime	NR	NR

Study	N	Mean Age	AChD Type or Severity	Adequacy	Antecedents	Outcomes
Overgaard et al (2014)	59	24	Single Ventricle	20% currently smoke, 85% drink, 26% binge drink $\geq 1x/month$. 5% currently abuse drugs	NR	NR
Moons et al (2006)	1976	26	NR	23% of men and 15% of women reported smoking regularly	Men more likely to use tobacco	NR
Engelfriet et al (2008)	3375	28	8 subgroups (ASD, VSD, Marfan, Aortic Coarctation, TOF, TGA, Fontan, Cyanotic)	9.3% current smokers, 4.2% past smokers	Men more likely to be current smokers and differences by defect type; no difference by age	Smoking related to TGA mortality only (HR=4.2)
Endocarditis Prevention						
Overgaard et al (2014)	59	24	Single Ventricle	20% no dental visit in past year	NR	NR
Reid et al (2008)	197	19-20	All moderate or severe CHD	Only 15% saw a dentist within the past year	NR	NR
Di Filippo et al (2006)	153	NR	39 corrected CHD, 35 palliated CHD, 79 with non-operated CHD	37% of endocarditis cases from dental or cutaneous causes	NR	NR

Study	N	Mean Age	ACHD Type or Severity	Adequacy	Antecedents	Outcomes
Knirsch et al (2005)	52	NR	NR	25% of cases related to dental procedures without antibiotic prophylaxis	NR	NR
Niwa et al (2005)	216	NR	97 non-operated 75 repaired 44 palliated	39% of identifiable causes of endocarditis either dental related or body piercing related	NR	NR
Obesity						
Maskatia et al (2013)	NR	NR	NR	NR	NR	Obesity is a modifiable risk factor associated with worsened biventricular systolic function and biventricular dilation
Zomer et al (2012)	1496	39	46% Simple 44% Moderate 10% Severe	30% overweight 10% obese	No differences with normative population; significant differences by CHD severity	NR
Zaidi et al (2011)	165	NR	NR	29% overweight 22% obese	NR	No influence on surgical mortality or morbidity, but is associated with post-op renal dysfunction in adults with complex CHD
Pemberton et al (2008)	NR	NR	NR	54% of adults with BMI >25 kg/m	NR	NR

Study	N	Mean Age	AChD Type or Severity	Adequacy	Antecedents	Outcomes
Pregnancy-Related						
Karamlou et al (2011)	26,973	27	Majority unknown (41%), combination of mild/moderate/severe CHD	50% of women delivered in non-specialty AChD centers	NR	NR
Vigl et al (2010)	536	29	TOF/TGA (22%), combination of mild/moderate/severe CHD	20% of women were using contraception methods that were contraindicated for their condition; 28% of women with high pregnancy-associated risks were not using contraception.	NR	NR
Moons et al (2009)	137	NR	NR	Only 38-57% of pregnant women with CHD regularly visited a cardiologist during pregnancy	NR	NR

*NR=Not Reported