

Appendix 1. Interview Topic Guide

Introduction:

“Thank you for speaking with me today.”

“The reason I am interviewing you is because I’m interested in understanding the role that numbers play in the management of Heart Failure.” “Particularly, I would like to understand how patients (like you) feel about receiving and using numerical information in the context of managing your disease.”

“What’s important for you to know is there are no right or wrong answers. I am recording this interview, but you should know that your answers will remain confidential nor will they affect your medical care here or anywhere else. Your healthcare provider will not receive information about this interview or your responses. At the end of the study, I plan to follow-up and share my findings with you.”

Opening question(s):

“Tell me, how long you’ve been coming to WCIMA?”

“How long have you had HF?”

Introductory statement:

“Since the purpose of this study is to assess how comfortable you are with numbers (in the context of your HF), I am going to give you 3 scenarios and ask you a few questions which pertain to each.

Again, there are no right and wrong answers. I simply am trying to understand your attitudes and beliefs towards numerical concepts and instructions that you may come across during visits with your doctor about HF. “

“The first scenario is about weight and water pills.”

Scenario 1

“Patients with HF are often asked to weigh themselves every day at home in order to monitor the amount of fluid in their body.”

(pause)

“Doctors tell patients that if they weigh themselves and notice a weight gain of 2 to 3 pounds in 1 day or 5 pounds in 1 week, that is a problem and a sign of increased fluid in the body. When that occurs, they are often asked to take higher doses of their water pills.”

(pause)

Question 1: What do you understand about the numerical instructions?

- Probe: Think back for a moment, has your doctor ever told you something like this?
- Probe: Think back to when you were in the hospital for HF, did doctors or nurses ever give you numerical instructions about monitoring your weight?

Question 2: How does it feel to use a scale at home to monitor your weight?

- Probe: When you step on a scale, what does the number mean to you?
- Probe: What is the first thing you think about if the number has changed?
- Probe: In terms of your HF, what should you do when you see that your weight has increased?
- Probe: Have you ever increased your water pill (or other medications) dose after noticing changes on the scale?
- Probe: Other than a scale, are there other ways that you keep track of your weight (or fluids in your body)?

Question 3: How confident are you that you could follow these numerical instructions?

- Probe: Why? Why not?
- Probe: Does monitoring your weight and adjusting your water pill doses feel like a difficult task to carry out?
- Probe: Would you require help to do so?
- Probe: Is there anything that might make recording your weight or noticing a significant gain or loss easier?

(pause)

“This next scenario I will read to you is about following a low salt diet.”

(pause)

Scenario 2

Patients with HF need to limit the amount of salt (sodium) they eat in order to avoid fluid buildup. Often, they are asked to follow a low salt diet, which would allow you to eat up to 3,000mg of salt per day.

(pause)

Let's say you go to the deli for lunch and buy 1 bag of potato chips (which is 170mg of salt) and a can of chicken soup (which is 820 mg of salt).

At dinnertime, let's say you eat a hot dog (which is 470mg of salt).

Given your 3,000mg limit, would you be able to eat a second hot dog?

(pause)

Question 1: What do you understand about what I just told you?

- Probe: Think back for a moment, has your doctor ever spoke to you about a low salt diet?
- Probe: Think back to when you were in the hospital for HF, did doctors or nurses ever give you numerical instructions about following a low salt diet?

Question 2: How does it feel to have to keep track of how much salt you eat each day?

- Probe: How comfortable are you the reading nutrition labels of the food you eat?
- Probe: What do you think about when you make food choices?
- Probe: What system do you use for deciding whether a food is salty?
- Probe: How does counting and adding the salt in each of the foods make you feel?

Question 3: How confident are you that you could follow these numerical instructions and maintain a low salt diet?

- Probe: Why? Why not?
- Probe: Does maintaining a low salt diet feel like a difficult task to carry out?
- Probe: Would you require help to do so?
- Probe: Is there anything that might make following a low salt diet easier?

“The final scenario I will read to you is about blood pressure.”

(pause)

Scenario 3:

Patients with HF often take medications for their blood pressure.

Doctors ask that patients with HF monitor their blood pressure at home with a blood pressure cuff and record it in a log.

(pause)

Yesterday, one of my patients called me because his blood pressure was 110/70. He thought the top number was too low and did not want to take his Coreg (also known as Carvedilol). I explained to him that if he felt well, it was OK to take the medication. I told him that patients with HF can tolerate lower blood pressures, but if the top number is less than 90mmHg or he is feeling lightheaded, he should not take his blood pressure medicine.

(pause)

Question 1: What do you understand about the numerical instructions?

- Probe: Think back for a moment, has your doctor ever told you something like this?
- Probe: Think back to when you were in the hospital for HF, did doctors or nurses ever give you numerical instructions about monitoring your blood pressure?

Question 2: What do you understand about the two numbers in a blood pressure measurement?

- Probe: As best as you can, tell me what the top and bottom number means to you?
- Probe: If you had to pay closer attention to one, which is more important for your HF and your health? (top or bottom). Why?

Question 2: How does it feel to use a blood pressure cuff at home to monitor your blood pressure?

- Probe: When your blood pressure is taken (or when you take it), what does the number mean to you?
- Probe: What blood pressure might be considered too high?

- Probe: What blood pressure might be considered too low?
- What is the first thing you think about when you see (or are told) what your blood pressure is?
- Probe: In terms of your HF, what should you do when you see that the top number is too high? Too low?
- Probe: Have you ever altered your medication regimen in response to seeing your blood pressure?

Question 3: How confident are you that you could follow these numerical instructions about blood pressure?

- Probe: Why? Why not?
- Probe: Does monitoring your blood pressure at home feel like a difficult task to carry out?
- Probe: Would you require help to do so?
- Probe: Is there anything that might make recording your blood pressure easier?
- Probe: Is there anything that might make taking (or adjusting) your blood pressure medications easier?
- Probe: How comfortable are you calling your doctor when you are unsure of what to do?

Ending question:

“I think what I heard today from you is _____, _____ and _____.

(pause)

Over the next few weeks I will be interviewing other patients and will be sure to circle back to you at the end of the study to share my findings with you.

“Before we end today, is there anything you want to tell me that I didn’t ask you?”

(pause)

END