

## **Supplemental Material**

**Supplemental Table 1.** COREQ 32-item checklist for focus groups.<sup>11</sup>

Item	Description/ Related Questions
<b>Domain 1: Research team and reflexivity</b>	
1. Interviewer/facilitator	Graciela Castillo
2. Credentials	MPH
3. Occupation	Senior Researcher
4. Gender	Female
5. Experience and training	Ms Castillo has conducted focus groups for over 10 years, in English and Spanish, and with participants of varying ages and health conditions.
6. Relationship established	None
7. Participant knowledge of the interviewer	None Ms Castillo introduced herself at the beginning of the focus group as a non-clinician and member of the research team.
8. Interviewer characteristics	Ms Castillo used her first name and led the focus group from a seated position at the conference table with the focus group participants. She established ground rules and expectations at the beginning of the groups. These included: one person speaking at a time, avoidance of cross-talk during the discussion, respect for others, and confidentiality of information discussed.
<b>Domain 2: Study Design</b>	
9. Methodological orientation and theory	Content analysis
10. Sampling	Purposive from individuals receiving in-center hemodialysis at 6 dialysis clinics in Carrboro, NC, Tucson, AZ and Seattle, WA who called central study telephone number and expressed study participation interest after viewing a recruitment sign in their dialysis clinics. Iterative purposive sampling was used to capture a range of participant characteristics (age, sex, race and education).
11. Method of approach	Participants were recruited until 10-12 participants for each of the 3 focus groups were scheduled.
12. Sample size	32 participants; 3 focus groups
13. Non-participation	See Figure 1. Among interested and qualifying individuals, the overall participation rate was 82% (77% for Carrboro, NC, 92% for Tucson, AZ and 79% for Seattle, WA).
14. Setting of data collection	Focus groups were conducted in dialysis clinic conference rooms in Carrboro, NC, Tucson, AZ and Seattle, WA. The conference room doors were closed to protect patient privacy. Participants sat at a conference table and were served light refreshments or lunch depending on the time of day.
15. Presence of non-participants	Two note-takers
16. Description of sample	See Table 1.
17. Interview guide	The semi-structured moderator guide was developed based on literature review and investigator team input. The moderator guide contained sections on symptom experiences in the past month (symptom type, quality and life impact) and individual and group symptom priority setting for the development of new or improved symptom-targeted therapies. See Supplemental Table 2 for the complete moderator guide.
18. Repeat interviews	N/A
19. Audio/visual recording	Audio-recorded
20. Field notes	The note-takers took notes on group dynamics and interactions as well as participant non-verbal body language. Participant demographic characteristics were self-reported.
21. Duration	90 minutes

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

22. Data saturation	Purposive sampling was employed in the study. Three focus groups in diverse geographic locations sufficiently identified consistent themes and patterns within all topic areas.
23. Transcriptions returned	Complete focus group transcripts were not shared with participants. However, summaries of each focus group were shared with participants within 4 weeks of focus group completion.
<b>Domain 3: Analysis and Findings</b>	
24. Number of data coders	2
25. Description of coding tree	The analytic team created node hierarchies within the analysis software and coded the data hierarchically, moving from general topics (parent nodes) to specific topics (child nodes), assigning illustrative quotes within each node.
26. Derivation of themes	The analytic team first developed a list of potential thematic codes based on the moderator guide sections. The team then reviewed the transcripts and identified early patterns in the data. They then revised the initial code list as appropriate and systematically coded the data based on the refined coding scheme. The team drew conclusions by identifying and interpreting coding patterns such as high-frequency codes and coding clusters. The summarized lists of top-reported and high-priority symptoms were determined based on the number of focus groups in which they were mentioned as well as their level of endorsement by participants. All codes and themes were developed iteratively and confirmed by consensus among the 2 analysts.
27. Software	NVivo (Burlington, MA)
28. Participant checking	At the end of each moderator guide section, the moderator probed for additional comments to elicit complete information. Additionally, she checked her understanding by providing summary statements and asking for clarifying feedback. She also followed the practice of repeating back participant comments to emphasize listening and clarify understanding and interpretation. At conclusion of each focus group, she asked for final thoughts so stakeholders had the opportunity to reflect on the focus group content in its entirety.
29. Quotations presented	See Tables 3 and 4.
30. Data and findings consistent	Consistent
31. Clarity of major themes	The identified symptoms were largely consistent across focus groups with a few symptoms identified by only 1 or 2 groups (e.g. vascular access pain, blurry vision). The symptom qualities (duration, frequency, unpredictability, and social and financial impact) that factored most into prioritization decision-making were consistent across focus groups. The symptom prioritization exercises resulted in similar prioritized symptom lists across focus groups.
32. Clarity of minor themes	N/A

Abbreviations: PCT, patient care technician; N/A, not applicable

## Supplemental Table 2. Focus group moderator guide.

### **Welcome and Ground Rules** (10 minutes)

#### **Welcome**

- Hello. Thank you for coming.
- **My name is** {NAME} and I'm the moderator for today's discussion. **I'm here with** {NAMES OF AIR/ASN NOTETAKERS}, who will be handing out materials and taking notes.
- I work for a company called the **American Institutes for Research**, or A-I-R, which is an independent non-profit research organization.
- Our group discussion today is part of a project sponsored by the American Society of Nephrology (ASN).
- ASN wants to know more about the types of symptoms that patients with kidney disease who are receiving hemodialysis in a facility experience and how these symptoms affect patients day-to-day. They also want to know what symptoms patients feel are most important to target for new or better therapies. This information will be used to help conduct research to develop new or better treatments to relieve symptoms. That's what we'll be talking about today.
- We are taping the discussion so that we can capture what was said, and not who said what. To protect your privacy, names won't be connected to what you say.

#### **Informed Consent**

- Each person has been provided an informed consent form. By signing this form, you agree to participate in this focus group. You will be given a copy of the form to take home. I'm going to read the form out loud for everyone now. [READ HIGHLIGHTS OF THE FORM] If you agree to participate, please sign your name at the bottom of the page with today's date. Please let me know if you have vision problems and need any help with the form. [COLLECT SIGNED FORMS; PROVIDE COPIES]

#### **Now, let's cover a few ground rules before we get started.**

#### **Ground rules** [Write bolded words on flip chart]

- We'll be here for an hour and a half and we're not going to take any formal breaks. But feel free to step out if you need to use the restroom or get something to drink. The bathroom is located {location of bathroom}. If possible, let's try to only have one person up at a time to keep the conversation moving. We want to be respectful of your time today.
- I want your honest opinions and reactions. Each of us has our own perspectives, opinions, and experiences; and all are important for us to learn. This also means that you may disagree or express an opinion that is different than others'. And, of course, we should be civil and maintain respect for each other – even when we disagree.
- We will be discussing a lot of topics and symptoms, and we want you to feel comfortable and safe because that will really help us get the best information and make the best recommendations. Please be respectful of each other. We ask that you do not discuss outside of this room what we talk about today, or share others' stories or experiences.
- We want to hear from everyone here. You don't need to raise your hand or wait for me to call on you before you speak. Let's just make sure only one person speaks at a time to make it easier for us to go back to the tape and hear what everyone said.
- Also, because we're recording, please try to speak in a voice at least as loud as the one I'm using now so that we can hear everyone on the tape.
- We have a lot to talk about today, so there may be times when I need to move the discussion along. Please understand that when I ask that we move to a new topic or speaker, I don't mean to be rude.
- Last little reminder, please turn off cell phones or set them to vibrate.
- Any questions before we get started? [RESPOND TO QUESTIONS ASKED]

**Great, let's get started.**

**Introductions (10 minutes)**

*Flip chart: First name; your favorite season of the year; how long you have been receiving hemodialysis*

1. To get started, let's go around and introduce ourselves. Please tell us:

- Your first name
- Your favorite season of the year
- How long you have been receiving hemodialysis

**Patients' Symptom Experiences & Priority-Setting (40 minutes)**

Thank you. It is nice to meet all of you.

First, to make sure that we're all on the same page, I'm going to explain what we mean by the word "symptoms".

Symptoms are any feelings of illness or changes in your body. There are physical symptoms, which have to do with how your body feels, and there are mood symptoms, which have to do with how you feel in your mind or your emotions.

Today, we'd like to learn more about the physical and mood symptoms you have experienced because of kidney disease or hemodialysis, how they have affected your lives, and which symptoms you think are MOST important to find new or better treatments for.

Let's start with the physical symptoms you have experienced.

*Physical Symptoms Experienced in the Past Month that Patients Feel have Affected Their Lives the Most*

**[MODERATOR NOTE: PASS OUT (2) INDEX CARDS TO EACH PARTICIPANT PRIOR TO MOVING ON TO QUESTION 2.]**

There should be 2 index cards in front of you.

Please write down the 2 physical symptoms that you have experienced in the past month and feel have affected your life the MOST. Please only write one symptom on each card. Also, please let us know if you need help writing your symptoms on the cards.

Okay, now that you have written down the 2 physical symptoms that you have experienced and feel have affected your life the most, I would like to ask for you to share those with the rest of the group.

Who wants to share what they wrote down?

**[MODERATOR NOTE: WRITE DOWN PARTICIPANTS' ANSWERS ON FLIP CHART. PLEASE PROBE ABOUT THEM SPECIFICALLY BY ASKING QUESTIONS 2-3 BELOW]**

2. [FOR EACH SYMPTOM, POSE 2A-2H TO THE GROUP AS NECESSARY THEN PROCEED TO Q3]: **How many people wrote this symptom down? [RECORD COUNT]**
- a. Why do you think these **symptoms have affected your life the most?**
  - b. What did you think about when deciding which symptoms have affected your life the most?
  - c. How **frequent** is this symptom?

- d. How **long** does it last?
  - e. How **bothersome** is this symptom?
  - f. How do these symptoms **limit your daily activities**?
  - g. How have these difficulties **impacted your quality of life**?
  - h. What would you **like to do that you can't** because of these symptoms?
3. Have you found any kind of treatment that helps relieve these symptoms? If so, what?
- a. What type of treatment would you like to have for these symptoms?

***Mood Symptoms Experienced in the Past Month that Patients Feel have Affected Their Lives the Most***

**[MODERATOR NOTE: PASS OUT (2) INDEX CARDS TO EACH PARTICIPANT PRIOR TO MOVING ON TO QUESTION 4.]**

**Thank you for sharing your experiences with physical symptoms. This is very helpful.**

**Now I would like for you to think about the mood symptoms you have experienced from kidney disease or hemodialysis in the past month.**

**We are going to give you 2 new index cards. Please write down the 2 mood symptoms that you have experienced in the past month and feel have affected your life the most. Please write one symptom on each of the index cards. Again, please let us know if you need any help with writing down your symptoms.**

**Okay, now that you have all written down your 2 mood symptoms, I would like to ask for you to share those with the rest of the group.**

**MODERATOR NOTE: WRITE DOWN PARTICIPANTS' ANSWERS ON FLIP CHART. PLEASE PROBE ABOUT THEM SPECIFICALLY BY ASKING QUESTIONS 4-5 BELOW.**

4. [FOR EACH SYMPTOM, POSE 4A-4H TO THE GROUP AS NECESSARY THEN PROCEED TO Q5]: **How many people wrote this symptom down? [RECORD COUNT]**
- a. Why do you think these **symptoms have affected your life the most**?
  - b. **What did you think about** when deciding which symptoms have affected your life the most?
  - c. How **frequent** is this symptom?
  - d. How **long** does it last?
  - e. How **bothersome** is this symptom?
  - f. How do these symptoms **limit your daily activities**?
  - g. How have these difficulties **impacted your quality of life**?
  - h. What would you **like to do that you can't** because of these symptoms?
5. Have you found any kind of treatment that helps relieve these symptoms? If so, what?
- a. What type of treatment would you like to have for these symptoms?

***Probe on Physical and Emotional Symptoms that Were Not Mentioned***

**[MODERATOR NOTE: PASS OUT COPIES OF THE SYMPTOM LIST SHOWN BELOW. LITERATURE SHOWS THE SYMPTOMS IN THE LIST BELOW ARE THE MOST COMMONLY NOTED BY PATIENTS WITH ESRD ON MAINTENANCE DIALYSIS THERAPY. IF ANY OF THESE ARE NOT BROUGHT UP BY PARTICIPANTS, PLEASE**

**PROBE ABOUT THEM SPECIFICALLY BUT ONLY AFTER COMPLETING THE INDEX CARD EXERCISE FOR PHYSICAL AND MOOD SYMPTOMS.]**

**[NOTETAKERS NOTE: PLEASE KEEP TRACK OF THOSE MENTIONED PRIOR TO PROBING AND ASSIST MODERATOR IN POSING UNMENTIONED PHYSICAL OR MOOD SYMPTOMS.]**

**Thank you for your input. It is very helpful. Now, I would like for you to look over this list that we're passing out. This is a list of physical and mood symptoms that are commonly reported by other patients like you [READ THE LIST OF SYMPTOMS ALOUD]. As a group here, you mentioned [ALL OF THEM/MOST OF THEM].**

[IF ALL OF THEM:] CONTINUE TO NEXT SECTION.

[IF MOST OF THEM:] **I'd like to talk about a few of these that we have not discussed.** [WRITE DOWN THE SYMPTOMS NOT DISCUSSED YET ON FLIP CHART].

6. Have you experienced any of these in the past month?
  - a. Do you feel that any of these symptoms should be added to the list of symptoms that have affected your lives the most?
  
7. Are there any other symptoms that we have not talked about that you would suggest adding to the list of symptoms that have affected your lives the most?
  - a. Please tell me about it. Why should it be added?

**Thanks again for your input. It is very useful and appreciated.**

***Symptoms Commonly Reported by Patients with Kidney Disease who are Receiving Hemodialysis***

**Physical Symptoms**

- Fatigue or low energy/weakness
- Dizziness/faintness/lightheadedness
- Skin: dry/itchy/color change
- Cough or shortness of breath
- Insomnia or trouble falling asleep
- Loss of appetite or poor appetite
- Nausea/vomiting
- Diarrhea/constipation
- Pain/aches/muscle cramps
- Numbness/tingling
- Swelling
- Sexual difficulty

**Mood Symptoms**

- Depression or feeling sad
- Feeling irritable
- Feeling nervous or anxious
- Difficulty concentrating
- Worrying

- Decreased interest in sex/loss of libido

#### **Group Prioritization of Symptoms (20 minutes)**

##### ***Physical and Emotional Symptoms that Patients Feel are Highest Priority to Target for the Development of New or Better Treatments***

Now, with the physical and mood symptoms that you feel have affected your lives the most and the reasons why you chose them in mind, let's talk about the symptoms that you feel are **MOST** important to find new or better treatments for. We hope to have treatments to relieve all of these symptoms one day, but we'd like to know which symptoms you think it is **MOST** important for researchers to find new or better treatments for. In other words, we'd like for you to let us know if you think some symptoms are higher priority than others.

**[MODERATOR: GO BACK TO MOST IMPORTANT SYMPTOMS LIST IN QUESTIONS 2 AND 5.]**

8. Let's go back to our list of symptoms that you feel have affected your lives the most. I'm going to say each symptom one at a time. When I do, I'd like for you to raise your hand if you think that symptom is high priority or most important. You can raise your hands for as many symptoms as you like, but please remember that we are trying to decide on the symptoms you think are the **MOST** important ones for researchers to find new or better treatments for.

**[MODERATOR: READ EACH SYMPTOM. SAY OUT LOUD THE NUMBER OF HANDS RAISED SO THAT IT IS RECORDED. WRITE THE COUNT/TALLY FOR EACH SYMPTOM ON FLIP CHART].**

**[MODERATOR NOTE: IF ALL PARTICIPANTS RAISE THEIR HANDS FOR ALL SYMPTOMS, ASK:]**

- a. What if there was only enough funding to find treatments or therapies for some of the symptoms on this list, but not for all? Which symptoms would you say are most important or high priority, knowing it can't be all of them?
9. I see that [SYMPTOMS WITH THE HIGHEST COUNT—LIST THE SYMPTOMS IN ORDER BASED ON THE COUNTS; ALSO LIST ANY THAT PARTICIPANTS CAN'T AGREE ON; CREATE NEW SHORTENED LIST OF HIGHEST PRIORITY SYMPTOMS ON FLIP CHART 6 IF NEEDED ] seem to be the **most important**. **What makes these symptoms the most important to address?**
  - a. IF ANY TIES: I see that symptom(s) X and Y are tied. Do you think that one is more of a priority than the other? If so, why?

10. Walk me through the **steps you went through to make that decision. What did you think about when you were deciding whether it should be high priority?**
11. Looking at our list of high priority symptoms and thinking about your own experiences, **how would your life be improved** if a treatment that worked was available for these symptoms?

**[MODERATOR NOTE: PROBE IF NECESSARY]**

- a. If these symptoms were to go away or got better, what would you be able to do that you can't do now?

Great, thank you again for your input it is very helpful.

**Closing (10 minutes)**

Before we end, I'd like to give everyone a chance to share any additional thoughts or comments about the things we talked about today.

**Is there anything that you didn't have a chance to say during our discussion today, or something that we didn't talk about that you wish we had, or any other thoughts you'd like to share with us?**

Thank you very much for participating in this discussion today. We appreciate your time and sharing of your personal experiences. This information will be very helpful as we move forward with additional research.

**HAND OUT INCENTIVES AND OBTAIN SIGNED RECEIPTS.**



**Supplemental Table 3.** Cognitive interview participant description.<sup>a</sup>

Characteristic	Participants (N=5)
<b>Age</b>	
20-29	1 (20%)
30-39	0 (0%)
40-49	2 (40%)
50-59	1 (20%)
60-69	0 (0%)
70-79	1 (20%)
<b>Gender</b>	
Male	3 (60%)
Female	2 (40%)
<b>Race / ethnicity</b>	
African American	3 (60%)
Caucasian	1 (20%)
Hispanic / Latino	1 (20%)
<b>Location</b>	
Seattle, WA	3 (60%)
Tucson, AZ	1 (20%)
Newark, DE	1 (20%)

<sup>a</sup> Values are presented as n (%). All characteristics were patient-reported.

### **Cognitive Interviewing Detailed Methods**

We conducted on-line cognitive interviews in May 2017 with hemodialysis patients in Tucson, AZ, Seattle, WA and Newark, DE to evaluate target population understanding and usability of the draft survey. Using Join.Me (LogMeIn, Boston, MA) online screen sharing and conference call software, an experienced interviewer conducted 60-minute web-based cognitive interviews. The site liaison facilitated computer access at each participant's dialysis clinic. The interviewer navigated the online survey via computer and asked interviewees to read items out-loud and used the think-aloud technique to respond to survey items. (Lewis, C. H. (1982). Using the "Thinking Aloud" Method in Cognitive Interface Design (Technical report). IBM. RC-9265.) Interviews were audio-recorded, and notes were taken by the interviewer. No incentive was provided.

Cognitive testing interviews were imported into a matrix in Microsoft Excel. Analysts first evaluated the data for themes by looking across participant responses for patterns of feedback. Second, analysts reviewed the information in each section to identify exemplar quotations. The audio recordings were used to supplement the notes. Identified patterns and participant feedback were used to update the on-line survey tool.

**Supplemental Table 4. Focus group symptom prioritization voting and ranking exercises informed survey contents.**

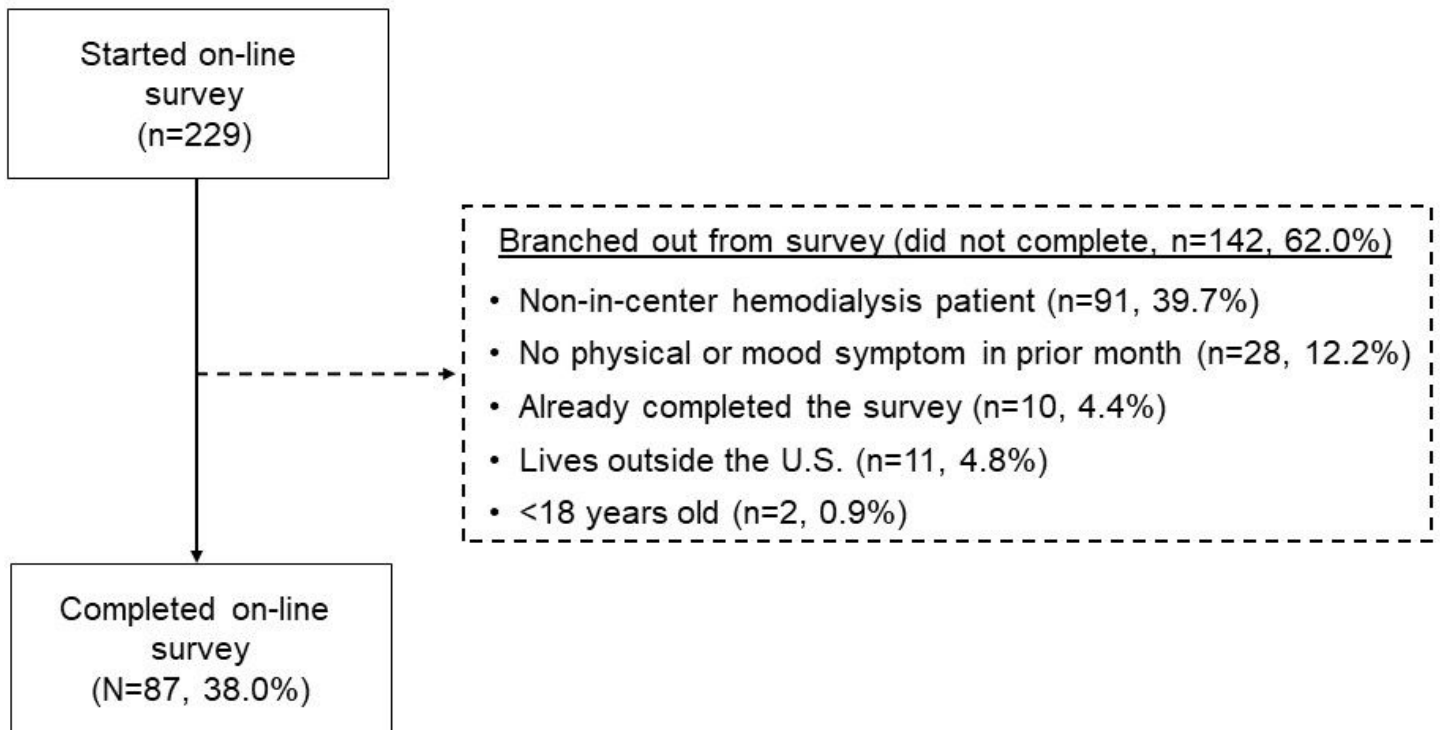
Top symptoms reported by focus group participants	Symptoms prioritized by focus group participants	Symptoms included in the survey <sup>a</sup>
<b>Physical Symptoms</b>		
1. Insomnia	1. Insomnia	1. Insomnia
2. Fatigue	2. Cramps	2. Cramps
3. Cramps	3. Fatigue	3. Fatigue
4. Nausea or vomiting	4. Nausea or vomiting	4. Nausea or vomiting
5. Body aches or pain	5. Body aches or pain	5. Body aches or pain
6. High or low BP	6. High or low BP <sup>b</sup>	
7. Problems with vascular access	7. Problems with vascular access	
8. Blurry vision	8. Blurry vision	
<b>Mood Symptoms</b>		
1. Anxiety	1. Anxiety	1. Anxiety
2. Depression	2. Depression	2. Depression
3. Irritability	3. Frustration	3. Frustration
4. Frustration	4. Worry	4. Worry
5. Worry	5. Confusion	5. Confusion
6. Feeling disrespected	6. Feeling disrespected <sup>b</sup>	
7. Confusion		

<sup>a</sup> The top 5 prioritized physical and top 5 prioritized mood symptoms were selected for survey inclusion. This decision was made to collect maximal information on both types of symptoms while minimizing survey burden.

<sup>b</sup> Deemed not to be symptoms by the steering committee and excluded from survey content consideration.

Abbreviations: BP, blood pressure.

**Supplemental Figure 1.** Flow diagram of survey respondents.



**Supplemental Table 5.** Complete survey results.

<b>What body symptoms have you had in the past month?</b>		
<b>Question 1. During the past month, did you have insomnia or trouble sleeping?</b>		
<b>N=86</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Yes</b>	62	72.1
<b>No</b>	24	27.9
<b>Question 1a. How often did you have insomnia or trouble sleeping during the past month?</b>		
<b>N=62</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Every day</b>	16	25.8
<b>2-3 times a week</b>	34	54.8
<b>Once a week</b>	8	12.9
<b>1-2 times a month</b>	2	3.2
<b>Other</b>	2	3.2
There were two other specified responses: 4-5 times a week (n=1) and 4-6 times a week (n=1).		
<b>Question 1b: In general, when did you have insomnia or trouble sleeping? Please pick all that apply. (Among those who reported having insomnia/trouble sleeping in Q1)</b>		
<b>N=62</b>		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
<b>Before hemodialysis</b>	29	46.8
<b>During hemodialysis</b>	21	33.9
<b>After hemodialysis</b>	48	77.4
<b>Question 1c: How often were you able to find relief for your insomnia or trouble sleeping?</b>		
<b>N=62</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Always</b>	0	0
<b>Usually</b>	18	29.0
<b>Sometimes</b>	35	56.5
<b>Never</b>	9	14.5
<b>Question 1d: How much did having insomnia or trouble sleeping limit your life such as being able to work or do things with friends and family?</b>		
<b>N=61</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Not at all</b>	4	6.6
<b>Very little</b>	13	21.3
<b>Somewhat</b>	24	39.3
<b>Quite a bit</b>	17	27.9
<b>A great deal</b>	3	4.9
<b>Question 2. During the past month, did you have muscle cramps?</b>		
<b>N=86</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Yes</b>	68	79.1
<b>No</b>	18	20.9
<b>Question 2a. How often did you have muscle cramps during the past month?</b>		
<b>N=68</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Every day</b>	4	5.9
<b>2-3 times a week</b>	24	35.3

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

Once a week	12	17.7
1-2 times a month	27	39.7
Other	1	1.5
There was one other specified response: One respondent stated “usually when removing too much fluid”.		
<b>Question 2b: In general, when did you have muscle cramps? Please pick all that apply. (Among those who reported having muscle cramps sleeping in Q2) N=68</b>		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
Before hemodialysis	7	10.3
During hemodialysis	50	73.5
After hemodialysis	39	57.4
<b>Question 2c: How often were you able to find relief for your muscle cramps? N=68</b>		
	<b>Frequency</b>	<b>Percent</b>
Always	18	26.5
Usually	25	36.8
Sometimes	23	33.8
Never	2	2.9
<b>Question 2d: How much did having muscle cramps limit your life such as being able to work or do things with friends and family? N=68</b>		
	<b>Frequency</b>	<b>Percent</b>
Not at all	22	32.4
Very little	19	27.9
Somewhat	20	29.4
Quite a bit	5	7.4
A great deal	2	2.9
<b>Question 3. During the past month, did you have fatigue (feeling tired or weak)? N=86</b>		
	<b>Frequency</b>	<b>Percent</b>
Yes	81	94.2
No	5	5.8
<b>Question 3a. How often did you have fatigue (feeling tired or weak) during the past month? N=81</b>		
	<b>Frequency</b>	<b>Percent</b>
Every day	30	37.0
2-3 times a week	37	45.7
Once a week	7	8.6
1-2 times a month	4	4.9
Other	3	3.7
There were three other specified responses: One respondent stated “always after dialysis”, another respondent stated “every dialysis day”, and a third respondent stated “usually morning after 3 <sup>rd</sup> shift dialysis.”		
<b>Question 3b: In general, when did you have fatigue (feeling tired or weak)? Please pick all that apply. (Among those who reported having fatigue (feeling tired or weak) in Q3) N=81</b>		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
Before hemodialysis	29	35.8
During hemodialysis	22	27.2
After hemodialysis	77	95.1

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

<b>Question 3c: How often were you able to find relief for your fatigue (feeling tired or weak)?</b> N=81		
	<b>Frequency</b>	<b>Percent</b>
<b>Always</b>	8	9.9
<b>Usually</b>	22	27.2
<b>Sometimes</b>	32	39.5
<b>Never</b>	19	23.5
<b>Question 3d: How much did having fatigue (feeling tired or weak) limit your life such as being able to work or do things with friends and family?</b> N=81		
	<b>Frequency</b>	<b>Percent</b>
<b>Not at all</b>	1	1.2
<b>Very little</b>	11	13.6
<b>Somewhat</b>	23	28.4
<b>Quite a bit</b>	29	35.8
<b>A great deal</b>	17	21.0
<b>Question 4. During the past month, did you have nausea or vomiting (throwing up)?</b> N=86		
	<b>Frequency</b>	<b>Percent</b>
<b>Yes</b>	40	46.5
<b>No</b>	46	53.5
<b>Question 4a. How often did you have vomiting (throwing up) during the past month?</b> N=40		
	<b>Frequency</b>	<b>Percent</b>
<b>Every day</b>	2	5.0
<b>2-3 times a week</b>	11	27.5
<b>Once a week</b>	7	17.5
<b>1-2 times a month</b>	15	37.5
<b>Other</b>	5	12.5
There were five other specified responses: "3-4 times a week"; "7 times"; "nausea almost every day"; "occasionally due to nasal condition"; and "twice yearly".		
<b>Question 4b: In general, when did you have vomiting (throwing up)? Please pick all that apply. (Among those who reported having vomiting (throwing up) in Q4)</b> N=40		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
<b>Before hemodialysis</b>	20	50.0
<b>During hemodialysis</b>	14	35.0
<b>After hemodialysis</b>	28	70.0
<b>Question 4c: How often were you able to find relief for your nausea or vomiting (throwing up)?</b> N=40		
	<b>Frequency</b>	<b>Percent</b>
<b>Always</b>	6	15.0
<b>Usually</b>	17	42.5
<b>Sometimes</b>	16	40.0
<b>Never</b>	1	2.5
<b>Question 4d: How much did having nausea or vomiting (throwing up) limit your life such as being able to work or do things with friends and family?</b> N=40		

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

	Frequency	Percent
Not at all	5	12.5
Very little	16	40.0
Somewhat	13	32.5
Quite a bit	3	7.5
A great deal	3	7.5
<b>Question 5. During the past month, did you have body aches or pain (other than cramps)?</b> N=86		
	Frequency	Percent
Yes	65	75.6
No	21	24.4
<b>Question 5a. How often did you have body aches or pain (other than cramps) during the past month?</b> N=65		
	Frequency	Percent
Every day	29	44.6
2-3 times a week	21	32.3
Once a week	6	9.2
1-2 times a month	8	12.3
Other	1	1.5
There were two other specified responses: One respondent who selected “every day” for Q5a also provided a written response, “back spasm”. The one respondent who selected “Other” for Q5a stated, “Probably caused by sitting in chair for 4 ½ hours, not actual dialysis”.		
<b>Question 5b: In general, when did you have body aches or pain (other than cramps)? Please pick all that apply.</b> (Among those who reported having body aches or pain (other than cramps) in Q5) N=65		
	Frequency (yes response)	% (yes response)
Before hemodialysis	37	56.9
During hemodialysis	31	47.7
After hemodialysis	60	92.3
<b>Question 5c: How often were you able to find relief for your body aches or pain (other than cramps)?</b> N=65		
	Frequency	Percent
Always	3	4.6
Usually	19	29.2
Sometimes	31	47.7
Never	12	18.5
<b>Question 5d: How much did having body aches or pain (other than cramps) limit your life such as being able to work or do things with friends and family?</b> N=65		
	Frequency	Percent
Not at all	5	7.7
Very little	9	13.9
Somewhat	27	41.5
Quite a bit	15	23.1
A great deal	9	13.9
<b>Question 6. During the past month, did you have another body symptom that we didn't ask about?</b> N=83		
	Frequency	Percent

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

<b>Yes</b>	32	38.6
<b>No</b>	51	61.5
Respondents listed several other body symptoms that they had experienced, including: bowel movement, depression, diabetic neuropathy, diarrhea, dry skin, eyes burning, feeling drained, head aches or migraines, itching heart palpitations, joint pain, low blood pressure, memory loss, mood swings, muscle spasms, restlessness, severe back pain, severe hip pain, feeling cold, swelling, dry mouth, arthritic like pain, itching, no sexual desires, and rashes.		
<b>Question 6a. How often did you have this other body symptom during the past month?</b>		
<b>N=32</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Every day</b>	10	31.3
<b>2-3 times a week</b>	13	40.6
<b>Once a week</b>	2	6.3
<b>1-2 times a month</b>	4	12.5
<b>Other</b>	3	9.4
There were three other specified responses: "depression", "each session for three wks", and "in winter colder".		
<b>Question 6b: In general, when did you have this other body symptom? Please pick all that apply. (Among those who reported having this other body symptom in Q6)</b>		
<b>N=32</b>		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
<b>Before hemodialysis</b>	13	40.6
<b>During hemodialysis</b>	21	65.6
<b>After hemodialysis</b>	28	87.5
<b>Question 6c: How often were you able to find relief for this other body symptom?</b>		
<b>N=32</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Always</b>	2	6.3
<b>Usually</b>	7	21.9
<b>Sometimes</b>	16	50.0
<b>Never</b>	7	21.9
<b>Question 6d: How much did having this other body symptom limit your life such as being able to work or do things with friends and family?</b>		
<b>N=32</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Not at all</b>	2	6.3
<b>Very little</b>	7	21.9
<b>Somewhat</b>	12	37.5
<b>Quite a bit</b>	6	18.8
<b>A great deal</b>	5	15.6
<b>What mood symptoms have you had in the past month?</b>		
<b>Question 7. During the past month, did you feel anxious or nervous?</b>		
<b>N=87</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Yes</b>	49	56.3
<b>No</b>	38	43.7
<b>Question 7a. How often did you feel anxious or nervous during the past month?</b>		
<b>N=49</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Every day</b>	10	20.4
<b>2-3 times a week</b>	22	44.9



Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

Once a week	10	20.4
1-2 times a month	7	14.3
Other	0	0
<b>Question 7b: In general, when did you feel anxious or nervous? Please pick all that apply. (Among those who reported feeling anxious or nervous in Q7) N=49</b>		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
Before hemodialysis	31	63.3
During hemodialysis	28	57.1
After hemodialysis	30	61.2
<b>Question 7c: How often were you able to find relief from feeling anxious or nervous? N=49</b>		
	<b>Frequency</b>	<b>Percent</b>
Always	7	14.3
Usually	14	28.6
Sometimes	20	40.8
Never	8	16.3
<b>Question 7d: How much did feeling anxious or nervous limit your life such as being able to work or do things with friends and family? N=49</b>		
	<b>Frequency</b>	<b>Percent</b>
Not at all	6	12.2
Very little	14	28.6
Somewhat	16	32.7
Quite a bit	11	22.5
A great deal	2	4.1
<b>Question 8. During the past month, did you feel sad or depressed? N=86</b>		
	<b>Frequency</b>	<b>Percent</b>
Yes	57	66.3
No	29	33.7
<b>Question 8a. How often did you feel sad or depressed during the past month? N=57</b>		
	<b>Frequency</b>	<b>Percent</b>
Every day	10	17.5
2-3 times a week	19	33.3
Once a week	12	21.1
1-2 times a month	14	24.6
Other	2	3.5
There were two other specified responses: One respondent stated "just today" and another stated "more than 2-3 times a week, but not every day".		
<b>Question 8b: In general, when did you feel sad or depressed? Please pick all that apply. (Among those who reported feeling sad or depressed in Q8) N=57</b>		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
Before hemodialysis	39	68.4
During hemodialysis	33	57.9
After hemodialysis	51	89.5
<b>Question 8c: How often were you able to find relief from feeling sad or depressed?</b>		

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

<b>N=57</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Always</b>	7	12.3
<b>Usually</b>	14	24.6
<b>Sometimes</b>	30	52.6
<b>Never</b>	6	10.5
<b>Question 8d: How much did feeling sad or depressed limit your life such as being able to work or do things with friends and family?</b>		
<b>N=57</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Not at all</b>	4	7.0
<b>Very little</b>	13	22.8
<b>Somewhat</b>	16	28.1
<b>Quite a bit</b>	16	28.1
<b>A great deal</b>	8	14.0
<b>Question 9. During the past month, did you feel frustrated or angry?</b>		
<b>N=86</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Yes</b>	54	62.8
<b>No</b>	32	37.2
<b>Question 9a. How often did you feel frustrated or angry during the past month?</b>		
<b>N=54</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Every day</b>	12	22.2
<b>2-3 times a week</b>	14	25.9
<b>Once a week</b>	14	25.9
<b>1-2 times a month</b>	13	24.1
<b>Other</b>	1	1.9
There was one other specified response: "Whenever the facility admin nurse is there."		
<b>Question 9b: In general, when did you feel frustrated or angry? Please pick all that apply. (Among those who reported feeling frustrated or angry in Q9)</b>		
<b>N=54</b>		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
<b>Before hemodialysis</b>	33	61.1
<b>During hemodialysis</b>	36	66.7
<b>After hemodialysis</b>	41	75.9
<b>Question 9c: How often were you able to find relief from feeling frustrated or angry?</b>		
<b>N=54</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Always</b>	6	11.1
<b>Usually</b>	14	25.9
<b>Sometimes</b>	23	42.6
<b>Never</b>	11	20.4
<b>Question 9d: How much did feeling frustrated or angry limit your life such as being able to work or do things with friends and family?</b>		
<b>N=54</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Not at all</b>	10	18.5

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

Very little	15	27.8
Somewhat	13	24.1
Quite a bit	6	11.1
A great deal	10	18.5
<b>Question 10. During the past month, did you feel worried?</b> N=85		
	<b>Frequency</b>	<b>Percent</b>
Yes	54	63.5
No	31	36.5
<b>Question 10a. How often did you feel worried during the past month?</b> N=54		
	<b>Frequency</b>	<b>Percent</b>
Every day	17	31.5
2-3 times a week	12	22.2
Once a week	12	22.2
1-2 times a month	12	22.2
Other	1	1.9
There was one other specified response: "Worried as much about personal issues such as financial and when I'll get a kidney as the actual treatments."		
<b>Question 10b: In general, when did you feel worried? Please pick all that apply.</b> (Among those who reported feeling worried in Q10) N=54		
	<b>Frequency (yes response)</b>	<b>% (yes response)</b>
Before hemodialysis	39	72.2
During hemodialysis	30	55.6
After hemodialysis	48	88.9
<b>Question 10c: How often were you able to find relief from feeling worried?</b> N=54		
	<b>Frequency</b>	<b>Percent</b>
Always	7	13.0
Usually	16	29.6
Sometimes	27	50.0
Never	4	7.4
<b>Question 10d: How much did feeling worried limit your life such as being able to work or do things with friends and family?</b> N=54		
	<b>Frequency</b>	<b>Percent</b>
Not at all	7	13.0
Very little	18	33.3
Somewhat	16	29.6
Quite a bit	10	18.5
A great deal	3	5.6
<b>Question 11. During the past month, did you feel confused?</b> N=87		
	<b>Frequency</b>	<b>Percent</b>
Yes	24	27.6
No	63	72.4
<b>Question 11a. How often did you feel confused during the past month?</b> N=24		

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

	Frequency	Percent
Every day	4	16.7
2-3 times a week	7	29.2
Once a week	6	25.0
1-2 times a month	7	29.2
Other	0	0
<b>Question 11b: In general, when did you feel confused? Please pick all that apply. (Among those who reported feeling confused in Q11) N=24</b>		
	Frequency (yes response)	% (yes response)
Before hemodialysis	13	54.2
During hemodialysis	7	29.2
After hemodialysis	19	79.2
<b>Question 11c: How often were you able to find relief from feeling confused? N=23</b>		
	Frequency	Percent
Always	3	13.0
Usually	4	17.4
Sometimes	13	56.5
Never	3	13.0
<b>Question 11d: How much did feeling confused limit your life such as being able to work or do things with friends and family? N=24</b>		
	Frequency	Percent
Not at all	3	12.5
Very little	7	29.2
Somewhat	8	33.3
Quite a bit	5	20.8
A great deal	1	4.2
<b>Question 12. During the past month, did you have another mood symptom that we didn't ask about? N=85</b>		
	Frequency	Percent
Yes	12	14.1
No	73	85.9
Respondents listed several other mood symptoms that they had experienced, including: anger and discomfort, feeling antsy, frustration, being afraid, irritable, feeling treatment is too long, dread of treatment, guilt, anxiety, and being uncomfortable.		
<b>Question 12a. How often did you have this other mood symptom during the past month? N=12</b>		
	Frequency	Percent
Every day	2	16.7
2-3 times a week	6	50.0
Once a week	1	8.3
1-2 times a month	2	16.7
Other	1	8.3
There was one other specified response: "each session for 3 weeks."		
<b>Question 12b: In general, when did you feel this other mood symptom? Please pick all that apply. (Among those who reported feeling this other mood symptom in Q12) N=12</b>		

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

	Frequency (yes response)	% (yes response)
Before hemodialysis	5	41.7
During hemodialysis	9	75.0
After hemodialysis	6	50.0
<b>Question 12c: How often were you able to find relief from this other mood symptom?</b>		
<b>N=12</b>		
	Frequency	Percent
Always	0	0
Usually	3	25.0
Sometimes	2	16.7
Never	7	58.3
<b>Question 12d: How much did having this other mood symptom limit your life such as being able to work or do things with friends and family?</b>		
<b>N=12</b>		
	Frequency	Percent
Not at all	5	41.7
Very little	1	8.3
Somewhat	4	33.3
Quite a bit	1	8.3
A great deal	1	8.3
<b>Most important body symptom to find better treatments for?</b>		
<b>Question 13: What is the <u>most important</u> body symptom to find better treatments for?</b>		
<i>Please pick only one.</i>		
<b>N=87</b>		
	Frequency	Percent
Insomnia or trouble sleeping	13	14.9
Muscle cramps	15	17.2
Fatigue (feeling tired or weak)	33	37.9
Nausea or vomiting (throwing up)	5	5.8
Body aches or pain (other than cramps)	11	12.6
Another body symptom	10	11.5
Respondents reported the following other body symptoms as most important to find better treatments for: back pain, high blood pressure, temperature at clinics, dry skin, feeling drained and dizzy, headache, itching and twitching, sleeping too much, and uncontrolled bowel movements.		
<b>Question 13a: What is the <u>top</u> reason why better treatments are needed for this symptom? <i>Please pick only one.</i></b>		
<b>N=87</b>		
	Frequency	Percent
It happens every time I get dialysis	13	14.9
It lasts a very long time	8	9.2
I can't predict when it will happen	20	22.9
It makes it hard for me to do basic things like cleaning, cooking, or getting dressed	17	19.5

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

<b>It keeps me from doing things I want to do with my friends or family</b>	18	20.7
<b>It keeps me from working or going to school</b>	6	6.9
<b>Other</b>	5	5.8
There were five other specified responses: “very painful and after it goes away still feel sore all day”; “hard to keep up with life”; chest cramping in particular is concerning, especially since I’m almost 70 years old”; “keeps me from sleeping”; and “Drs. Often think pain is all in your head and will not treat pain adequately”.		
<b>Question 13b: What kind of treatment or support would <u>best</u> help you deal with this symptom? Please pick only one.</b> <b>N=86</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>a medicine that provides relief</b>	53	61.6
<b>a device that supports you or helps you keep track of the symptom (for example, something you could wear or put on your phone to help you reduce or keep track of the symptom</b>	5	5.8
<b>Talking to a professional who can help with the body symptom</b>	8	9.3
<b>Talking to other people who have the same body symptom</b>	7	8.1
<b>Other</b>	13	15.1
There were 12 other specified responses: “availability of nocturnal dialysis”; “better determination of appropriate weight to remove during treatment”; “better method of treatment and fluid removal other than “dry weight; an anachronism”; “don’t take off too much fluid”; “I feel they are stilling my blood and try to replace it with some fluid that just makes me pee much more”; “Xanax before sleep-lowest dose”; “chemicals in dialy machine”; “get specific detailed information regarding muscle cramps to many theories given by health care providers”; “meditation”; “my wife gives me massages”; “massage chairs”; and “none of these”.		
<b>What is the most important mood symptom to find better treatments for?</b>		
<b>Question 14: What is the most important mood symptom to find better treatments for? Please pick only one.</b> <b>N=82</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>Feeling anxious or nervous</b>	18	22.0
<b>Feeling sad or depressed</b>	31	37.8
<b>Feeling frustrated or angry</b>	19	23.2
<b>Feeling worried</b>	5	6.1
<b>Feeling confused</b>	5	6.1
<b>Another mood symptom</b>	4	4.9
There were four other specified responses for this question: One respondent stated, “feeling spaced out”; another stated, “may simply be age 86”; another stated “no problems” and a fourth respondent responded “N/a”.		
<b>Question 14a: What is the <u>top</u> reason why better treatments are needed for this symptom? Please pick only one.</b> <b>N=82</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>It happens every time I get dialysis</b>	15	18.3
<b>It lasts a very long time</b>	15	18.3
<b>I can’t predict when it will happen</b>	20	24.4

Supplemental material is neither peer-reviewed nor thoroughly edited by CJASN. The authors alone are responsible for the accuracy and presentation of the material.

<b>It makes it hard for me to do basic things like cleaning, cooking, or getting dressed</b>	4	4.9
<b>It keeps me from doing things I want to do with my friends or family</b>	17	20.7
<b>It keeps me from working or going to school</b>	1	1.2
<b>Other</b>	10	12.2
There were nine other specified responses: “The cramps make me feel like giving up and stop doing dialysis”; “I am not usually sad but if I were I would want it fixed”; “none of these”; “difficult to deal with other people”; “knowing my health is only getting worse”; “long-term ancillary issue, financial concerns, no easy fix”; “It affects every aspect of life”; “I don’t have these symptoms but if I did I would want them fixed”; “raises my blood pressure “.		
<b>Question 14b: What kind of treatment or support would best help you deal with this symptom? <i>Please pick only one.</i></b> <b>N=82</b>		
	<b>Frequency</b>	<b>Percent</b>
<b>a medicine that proves relief</b>	28	34.1
<b>a device that supports you or helps you keep track of the symptom (for example, something you could wear or put on your phone to help you reduce or keep track of the symptom</b>	4	4.9
<b>Talking to a professional who can help with the mood symptom</b>	22	26.8
<b>Talking to other people who have the same mood symptom</b>	15	18.3
<b>Other</b>	13	15.9