

Supplementary Table 1. Interview Guides for Pain Interference Domain

PAIN INTERFERENCE CHILD SEMI-STRUCTURED INTERVIEW (CANCER SURVIVOR)*
<p><u>Introduction to the Interview</u></p> <p>Hi, my name is _____ and I'm a _____ at _____.</p> <p>Thank you again for agreeing to do this interview with me today. If it is ok, I will start the tape recorder.</p> <p>[START TAPE RECORDER, VERBALLY RECORD:</p> <ul style="list-style-type: none"> • DATE & TIME OF INTERVIEW • FIRST NAME OF CHILD • YOUR NAME] <p><u>VERBAL ASSENT</u></p> <p><u>CHILD'S NAME</u>, we are glad that you want to do this interview and that your Mom (Dad/Parents) have given their permission for you to be in this study. It should about 30 minutes.</p> <p>We are doing these interviews to learn more about what young people think and feel about their health.</p> <p>Even though I will ask you some questions, this is not a test at all. We want to hear your ideas and experiences. There are no right or wrong answers, just what seems right to you.</p> <p>We are tape recording and also taking notes. My notes help me keep track during the interview and the recording gives us a way to listen again if we need to. When this study is over we will destroy the tape recordings and our notes.</p> <p>The questions I'm going to ask you are about how you think about health and things related to health, so some of them are personal or private. If you don't want to answer a question, that's fine. If you want to take a break or even stop, just let me know.</p> <p>We will only use your first name during the interview and in our notes. I will not tell anyone here or in your family about anything that you said. Information from research is always private and confidential. There is only one exception. If you tell me that you are being harmed or might be harmed, then, together we will talk to someone to get the help you need to be safe.</p> <p>Do you have any questions for me before we begin?</p>
<p><u>Rapport development</u></p> <p>Before we begin, I'd like to learn a little more about you...</p> <ul style="list-style-type: none"> • <i>So how old are you now?</i> • <i>What are some of your favorite things to do after school? And on the weekends?</i>

Statement of interview focus

We want to talk with you about your experiences after stopping your cancer treatment. So, can you tell me when you were diagnosed with cancer? How old were you? [Write in the response here: _____ years old.]

Now I want you to think about your health and life over the past two years.

First I would like to talk with you about how pain has affected you over the past two years.

Elicit reactions to key health words/phrases**Pain description:**

- First, let's start by you telling me what you think about when you hear the word pain.
 - How does pain feel to you?
 - What are some words you use to describe your pain?

Be sure that participant describes pain experiences, not just general experiences of feeling ill or uncomfortable.

General pain interference:

Now I want you to think about all the things you do in your life:

- How did having pain affect what you could do in your life?

Pain experience #1: (Related to cancer survivorship)

Now let's think about a specific time when you had a lot of pain. Remember we are asking you to think about the past two years. We are really interested in knowing how pain affects kids after they stop their cancer treatment.

- What things couldn't you do that you normally would be able to do?
- How does pain affect the things you like to or the way that you have fun?
- What problems does the pain cause for you?

If the participant does not talk about how pain has affected any parts of their life, proceed to ask the following more specific, open-ended questions.

Mobility interference:

- How did the pain affect how you can move and get around?

Emotional interference:

- How does the pain affect the feelings that you have?

Cognitive interference:

- How does pain affect how you think?

Social interference:

- How does pain affect what you do with your friends and family?

School interference:

- How does pain affect what you do at school?

Pain experience #2: (Related to Cancer survivorship)

Now let's think about another time when you had a lot of pain after your cancer treatment.

What are some things you couldn't do in your life?

- What things couldn't you do that you normally would be able to do?
- How does pain affect the things you like to or the way that you have fun?
- What problems does the pain cause for you?

If the participant does not talk about how pain has affected any parts of their life, proceed to ask the following more specific, open-ended questions.

Mobility interference:

- How did the pain affect how you can move and get around?

Emotional interference:

- How does the pain affect the feelings that you have?

Cognitive interference:

- How does pain affect how you think?

Social interference:

- How does pain affect what you do with your friends and family?

School interference:

- How does pain affect what you do at school?

* Replace the word "you" by the phrase "your child" for interviewing caregivers

Supplementary Table 2. Interview Guides for Fatigue Domain

FATIGUE CHILD SEMI-STRUCTURED INTERVIEW (CANCER SURVIVOR)*
<p><u>Introduction to the Interview</u></p> <p>Hi, my name is _____ and I'm a _____ at _____.</p> <p>Thank you again for agreeing to do this interview with me today. If it is ok, I will start the tape recorder.</p> <p>[START TAPE RECORDER, VERBALLY RECORD:</p> <ul style="list-style-type: none"> • DATE & TIME OF INTERVIEW • FIRST NAME OF CHILD • YOUR NAME] <p><u>VERBAL ASSENT</u></p> <p><u>CHILD'S NAME</u>, we are glad that you want to do this interview and that your Mom (Dad/Parents) have given their permission for you to be in this study. It should take about 30 minutes.</p> <p>We are doing these interviews to learn more about what young people think and feel about their health.</p> <p>Even though I will ask you some questions, this is not a test at all. We want to hear your ideas and experiences. There are no right or wrong answers, just what seems right to you.</p> <p>We are tape recording and also taking notes. My notes help me keep track during the interview and the recording gives us a way to listen again if we need to. When this study is over we will destroy the tape recordings and our notes.</p> <p>The questions I'm going to ask you are about what you think about health and things related to health, so some of them are personal or private. If you don't want to answer a question, that's fine. If you want to take a break or even stop, just let me know.</p> <p>We will only use your first name during the interview and in our notes. I will not tell anyone here or in your family about anything that you said. Information from research is always private and confidential. There is only one exception. If you tell me that you are being harmed or might be harmed, then, together we will talk to someone to get the help you need to be safe.</p> <p>Do you have any questions for me before we begin?</p>
<p><u>Rapport development</u></p> <p>Before we begin, I'd like to learn a little more about you...</p> <ul style="list-style-type: none"> • <i>So how old are you now?</i> • <i>What are some of your favorite things to do after school? And on the weekends?</i>

Statement of interview focus

We want to talk with you about your experiences after stopping your cancer treatment. So, can you tell me when you were diagnosed with cancer? How old were you? [Write in the response here: _____ years old.]

Now I want you to think about your life over the past two years.

First I would like to talk with you about how being tired has affected you over the past two years.

Elicit reactions to key health words/phrases**Fatigue description:**

- First, let's start by you telling me what you think about when you hear the word 'fatigue' or 'being tired'.
 - How does being tired feel to you?
 - What are some words you use to describe being tired?

General fatigue interference:

Now I want you to think about all the things you do in your life:

- How does being tired affect what you can do in your life?

Fatigue experience #1: (Related to surviving cancer)

Now let's think about a specific time when you extremely tired. Remember we are asking you to think about the past two years. We are really interested in knowing how being tired affects kids after they stop their cancer treatment.

- What things couldn't you do that you normally would be able to do?
- How does being tired affect the things you like to or the way that you have fun?
- What problems do you have from being very tired?

If the participant does not talk about how fatigue has affected any parts of their life, proceed to ask the following more specific, open-ended questions. If no experiences of fatigue, move on to another domain.

Mobility interference:

- How did being tired affect how you can move and get around?

Emotional interference:

- How does being tired affect the feelings that you have?

Cognitive interference:

- How does being tired affect how you think?

Social interference:

- How does being tired affect what you do with your friends and family?

School interference:

- How does being tired affect what you do at school?

Fatigue experience #2: (Related to surviving cancer)

Now let's think about another time when you were extremely tired in the time since your cancer treatment. What are some things you couldn't do in your life?

- What things couldn't you do that you normally would be able to do?
- How does being tired affect the things you like to or the way that you have fun?
- What problems do you have from being very tired?

If the participant does not talk about how fatigue has affected any parts of their life, proceed to ask the following more specific, open-ended questions.

Mobility interference:

- How did being tired affect how you can move and get around?

Emotional interference:

- How does being tired affect the feelings that you have?

Cognitive interference:

- How does being tired affect how you think?

Social interference:

- How does being tired affect what you do with your friends and family?

School interference:

- How does being tired affect what you do at school?

* Replace the word "you" by the phrase "your child" for interviewing caregivers

Supplementary Table 3. Interview Guides for Psychological Stress Domain

PSYCHOLOGICAL STRESS RESPONSE CHILD SEMI-STRUCTURED INTERVIEW (CANCER SURVIVOR)*
<p><u>Definition of Stress Response pediatric item bank:</u> How stress affects a child's somatic and cognitive/psychological states.</p> <p><u>Introduction to the Interview</u></p> <p>Hi, my name is _____ and I'm a _____ at _____.</p> <p>Thank you again for agreeing to do this interview with me today. If it is ok, I will start the tape recorder.</p> <p>[START TAPE RECORDER, VERBALLY RECORD:</p> <ul style="list-style-type: none"> • DATE & TIME OF INTERVIEW • FIRST NAME OF CHILD • YOUR NAME] <p><u>CHILD'S NAME</u>, we are glad that you want to do this interview and that your Mom (Dad/Parents) have given their permission for you to be in this study. It should take about 30-40 minutes.</p> <p>We are doing these interviews to learn more about what young people think and feel about their health.</p> <p>Even though I will ask you some questions, this is not a test at all. We want to hear your ideas and experiences. There are no right or wrong answers, just what seems right to you.</p> <p>We are tape recording and also taking notes. My notes help me keep track during the interview and the recording gives us a way to listen again if we need to. When this study is over we will destroy the tape recordings and our notes.</p> <p>The questions I'm going to ask you are about what you think about health and things related to health, so some of them are personal or private. If you don't want to answer a question, that's fine. If you want to take a break or even stop, just let me know.</p> <p>We will only use your first name during the interview and in our notes. I will not tell anyone here or in your family about anything that you said. Information from research is always private and confidential. There is only one exception. If you tell me that you are being harmed or might be harmed, then, together we will talk to someone to get the help you need to be safe.</p> <p>Do you have any questions for me before we begin?</p>
<u>Rapport development</u>

Before we begin, I'd like to learn a little more about you... [Ask whatever questions seem appropriate, examples:]

- *So how old are you now?*
- *What are some of your favorite things to do after school? And on the weekends?*

Statement of interview focus

We want to talk with you about your experiences after stopping your cancer treatment. So, can you tell me when you were diagnosed with cancer? How old were you? [Write in the response here: _____ years old.]

Now I want you to think about your health and life over the past two years.

First I would like to talk with you about how stress has affected you over the past two years.

Elicit reactions to key health words/phrases

First, let's start by you telling me what you think about when you hear the word 'stress' or 'being challenged'.

- How does stress feel to you?
- What are some words you use to describe being 'stressed'?

Elicit description of Stress experience

[Stress experience #1]

Now let's think about a specific time when you had a lot of stress. Remember we are asking you to think about the past two years. We are really interested in knowing how stress affects kids after they stop their cancer treatment.

(use 'being challenged' if needed.)

[Give time to think]

Can you tell me about that?

[If child describes an ongoing stressor, help him/her think about a specific experience, e.g., "can you think of a time when you felt really stressed about ___?"]

Context

- What was happening?
- When was that?

Cognitive stress response

- When you were stressed what thoughts did you have?
 - What was going through your mind?
 - How did stress affect your thinking?

Emotional stress response

- When you were stressed what feelings did you have?
 - Tell me about the emotions you felt.

Behavioral stress response

- How did you act when you were feeling stressed?
- How would other people know that you were feeling stressed?

Body response

- How did your body feel when you were stressed?
 - What changes did you notice?

Summarize – **What other ways do you think that having stress affected you?**

[STRESS EXPERIENCE #2]

Now let's think about another time when you had a lot of stress after your cancer treatment.

[Give time to think]

Tell me about what happened.

[If child describes an ongoing stressor, help him/her think about a specific experience, e.g., “can you think of a time when you felt really stressed about ___?”]

Context

- What was happening?
- When was that?

Cognitive stress response

- When you were stressed what thoughts did you have?
 - What was going through your mind?
 - What were you thinking?

Emotional stress response

- When you were stressed what feelings did you have?
 - Tell me about the emotions you felt.

Behavioral stress response

- How did you act when you were feeling stressed?
- How would other people know that you were feeling stressed?

Body response

- How did your body feel when you were stressed?
 - What changes did you notice?

Summarize – **What other ways do you think that having stress affected you?**

* Replace the word “you” by the phrase “your child” for interviewing caregivers

Supplementary Table 4. Interview Guides for Perceived Stigmatization Domain

STIGMA CHILD SEMI-STRUCTURED INTERVIEW (CANCER SURVIVOR)*
<p><u>Definition of Stigma:</u> Perceptions of self and publicly enacted negativity, prejudice, and discrimination as a result of disease-related manifestations.</p> <p><u>Introduction to the Interview</u></p> <p>Hi, my name is _____ and I'm a _____ at _____.</p> <p>Thank you again for agreeing to do this interview with me today.</p> <p>If it is ok, I will start the tape recorder.</p> <p>[START TAPE RECORDER, VERBALLY RECORD:</p> <ul style="list-style-type: none"> • DATE & TIME OF INTERVIEW • FIRST NAME OF CHILD • YOUR NAME] <p><u>CHILD'S NAME,</u> we are glad that you want to do this interview and that your Mom (Dad/Parents) have given their permission for you to be in this study. It should take about 30 minutes.</p> <p>We are doing these interviews to learn more about what young people think and feel about their health.</p> <p>Even though I will ask you some questions, this is not a test at all. We want to hear your ideas and experiences. There are no right or wrong answers, just what seems right to you.</p> <p>We are tape recording and also taking notes. My notes help me keep track during the interview and the recording gives us a way to listen again if we need to. When this study is over we will destroy the tape recordings and our notes.</p> <p>The questions ask what you think about health and things related to health, so some of them are personal or private. If you don't want to answer a question, that's fine. If you want to take a break or even stop, just let me know.</p>

We will only use your first name during the interview and in our notes. I will not tell anyone here or in your family about anything that you said. Information from research is always private and confidential. There is only one exception. If you tell me that you are being harmed or might be harmed, then, together we will talk to someone to get the help you need to be safe.

Do you have any questions for me before we begin?

Rapport development

Before we begin, I'd like to learn a little more about you... [Ask whatever questions seem appropriate, examples:]

- *So how old are you now?*
- *What are some of your favorite things to do after school? And on the weekends?*

Statement of interview focus

We want to talk with you about your experiences after stopping your cancer treatment. So, can you tell me when you were diagnosed with cancer? How old were you? [Write in the response here: _____ years old.]

Now I want you to think about your life over the past two years.

First, I want to talk about whether you feel that people have treated you differently than others because you had cancer. I'm also interested in knowing how having cancer might have changed how you see and think about yourself.

Perceptions of publicly enacted negativity (Experience #1):

Since completing your cancer treatment, do you think people see you or treat you differently than others?

- Can you tell me about that?

Since completing your cancer treatment, can you tell me about a specific time when you thought people may have treated you differently than other kids because you had cancer?

Context:

- When was that? (etc.)

Prompts (if not described in experience):

- How did you feel when _____?
- What you were thinking when _____?
- How did you act when _____?

Summarize - Is there anything else that you can remember about that experience?

[Experience #2] (If first experience positive, focus on negative exp.)

Now I'd like you to think about another time, in the past two years, when other kids or adults may have treated you differently because you had cancer.

[Give time to think]

Can you describe that for me?

Context:

- When was that? (etc.)

Prompts (if not described in experience):

- How did you feel when _____?
- What you were thinking when _____?
- How did you act when _____?

Summarize - Is there anything else that you can remember about that experience?

Perceptions of Self and Publicly enacted negativity:

Thanks for sharing that with me. We're now going to talk about how you see yourself.

Do you think that the experiences that you've described to me (about being treated differently by others) have changed the way you see or think about yourself?

If yes: In what ways?

[Give time to think]

Potential prompts:

Can you give me any examples?

Thank you for sharing that with me.

* Replace the word "you" by the phrase "your child" for interviewing caregivers

Supplementary Table 5. Interview Guides for Meaningful and Purpose Domain

MEANING & PURPOSE CHILD SEMI-STRUCTURED INTERVIEW (CANCER SURVIVOR)*
<p><u>Introduction to the Interview</u></p> <p>Hi, my name is _____ and I'm a _____ at _____.</p> <p>Thank you again for agreeing to do this interview with me today.</p> <p>If it is ok, I will start the tape recorder.</p> <p>[START TAPE RECORDER, VERBALLY RECORD:</p> <ul style="list-style-type: none"> • DATE & TIME OF INTERVIEW • FIRST NAME OF CHILD • YOUR NAME] <p><u>CHILD'S NAME</u>, we are glad that you want to do this interview and that your Mom (Dad/Parents) have given their permission for you to be in this study. It should take about 30-40 minutes.</p> <p>We are doing these interviews to learn more about what young people think and feel about their health.</p> <p>Even though I will ask you some questions, this is not a test at all. We want to hear your ideas and experiences. There are no right or wrong answers, just what seems right to you.</p> <p>We are tape recording and also taking notes. My notes help me keep track during the interview and the recording gives us a way to listen again if we need to. When this study is over we will destroy the tape recordings and our notes.</p> <p>The questions I'm going to ask you are about what you think about health and things related to health, so some of them are personal or private. If you don't want to answer a question, that's fine. If you want to take a break or even stop, just let me know.</p>

We will only use your first name during the interview and in our notes. I will not tell anyone here or in your family about anything that you said. Information from research is always private and confidential. There is only one exception. If you tell me that you are being harmed or might be harmed, then, together we will talk to someone to get the help you need to be safe.

Do you have any questions for me before we begin?

Statement of Interview focus

We want to talk with you about your experiences after stopping your cancer treatment. So, can you tell me when you were diagnosed with cancer? How old were you? [Write in the response here: _____ years old.]

Now I want you to think about your health and life over the past two years.

(First) I would like to talk with you about happiness and feeling optimistic in the past two years.

Having a “good” life

What does it mean to say this?: This kid has a “good” life?

- What do kids do when they have a good life?
- How do kids feel when they have a good life?

[Probe until child is unable to identify other ways that kids have a good life or feel when they have a good life.]

In what ways do you have a good life?

[Probe until child identifies 3 or 4 ways in which his/her life is good.]

Is there anything you want to change about your life?

Meaning

What does it mean to say ‘this kid has a “meaningful” life’?

What are the most important parts of life that give you meaning?

Do you think the meaning in your life has changed at all since having cancer? How so?

[Elicit as many responses to this question as possible]

Purpose

What does it mean to say that ‘this kid’s life has purpose’?

What are the most important parts of your life that give you purpose?

Do you think your purpose has changed at all since having cancer? How so?

[Elicit as many responses to this question as possible]

Summarize – Is there anything else that you can remember or stands out for you about that experience?

* Replace the word “you” by the phrase “your child” for interviewing caregivers

Supplementary Table 6. Mean Numbers of Meaning Units and Meaningful Concepts

PRO Domains	Sample Size (Survivor/Caregiver)	Mean Number Meaning Units (Survivor/Caregiver)	Mean Number Meaningful Concepts (Survivor/Caregiver)
Pain Interference	18/13	13.6/10.5	10.4/9.2
Fatigue	21/13	13.1/11.3	11.6/10.6
Psychological Stress	19/14	6.2/8.4	6.6/8.4
Stigma	14/8	7.2/4.5	4.5/4.6
Meaning and Purpose	20/6	17.4/10.3	10.9/9.8

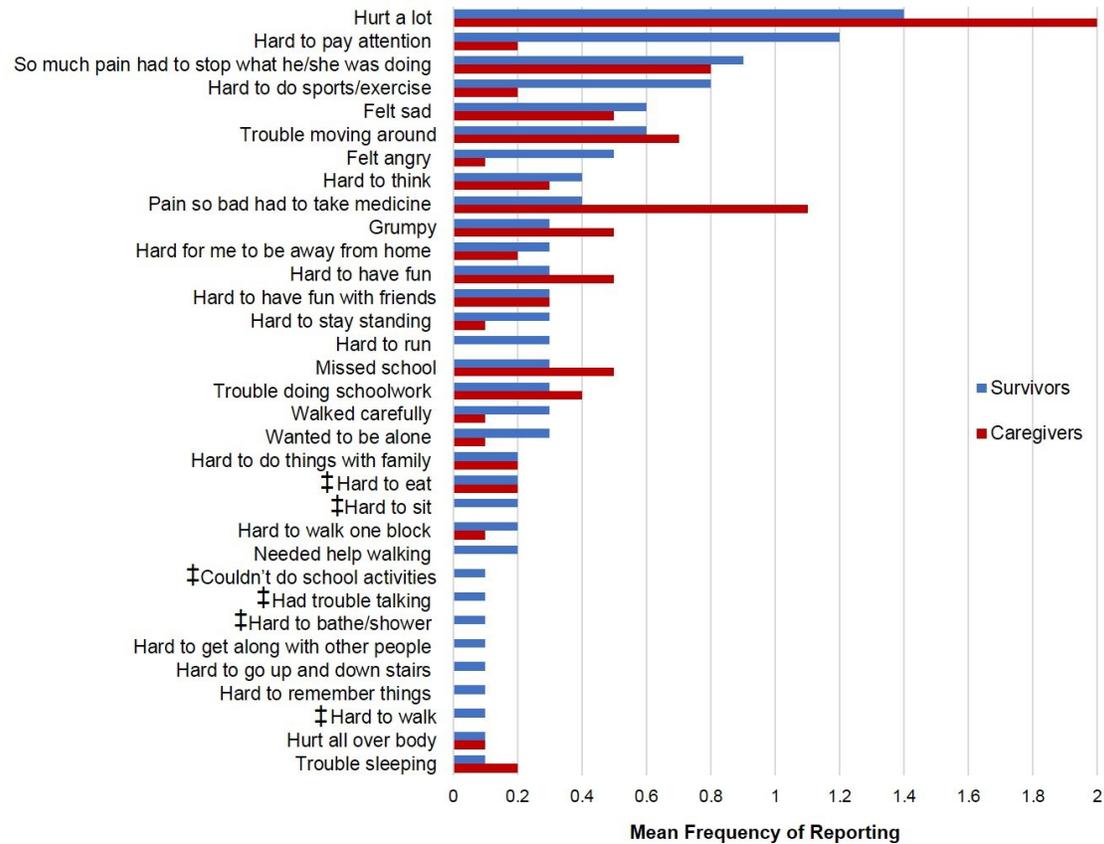
Supplementary Table 7 Comparisons of Total Meaningful Concepts per PRO Domain by Four Cancer Diagnoses

PRO Domains	Sample Size	Means (SD) of Frequency				Difference Across Diagnoses	Difference Between Survivors/Caregivers & Cancer Diagnoses
		N	CNS	HL/NHL	Leukemia	Solid Tumor	P-value
Pain interference							
Survivors	18	8.0 (1.7)	18.0 (NA)	15.6 (4.0)	8.0 (3.4)	0.003	0.016
Caregivers	13	10.4 (5.0)	(-)	12.0 (0.0)	8.0 (4.9)	0.612	
Fatigue							
Survivors	21	10.0 (6.0)	(-)	13.2 (6.4)	10.4 (5.5)	0.551	0.728
Caregivers	13	14.0 (4.0)	(-)	9.4 (5.9)	9.8 (6.1)	0.517	
Stress							
Survivors	19	4.3 (5.8)	9.3 (5.0)	6.3 (2.9)	6.5 (4.4)	0.597	0.339
Caregivers	14	7.5 (2.1)	6.0 (1.4)	12.0 (1.0)	7.7 (3.0)	0.089	
Stigma							
Survivors	14	7.5 (6.1)	6.0 (NA)	6.5 (3.5)	5.4 (3.2)	0.909	0.919
Caregivers	8	2.5 (3.5)	5.0 (NA)	4.0 (NA)	2.5 (0.7)	0.717	
Meaning & purpose							
Survivors	20	8.5 (7.8)	12.0 (3.5)	11.3 (2.9)	10.7 (3.4)	0.749	0.377
Caregivers	16	6.0 (0.0)	8.7 (2.5)	13.5 (7.0)	9.1 (2.7)	0.203	

Abbreviation: SD, Standard Deviation; CNS, Central Nervous System; HL, Hodgkin Lymphoma; NHL, Non-Hodgkin Lymphoma

Note, (-): no report; (NA): not able to estimate due to only one report

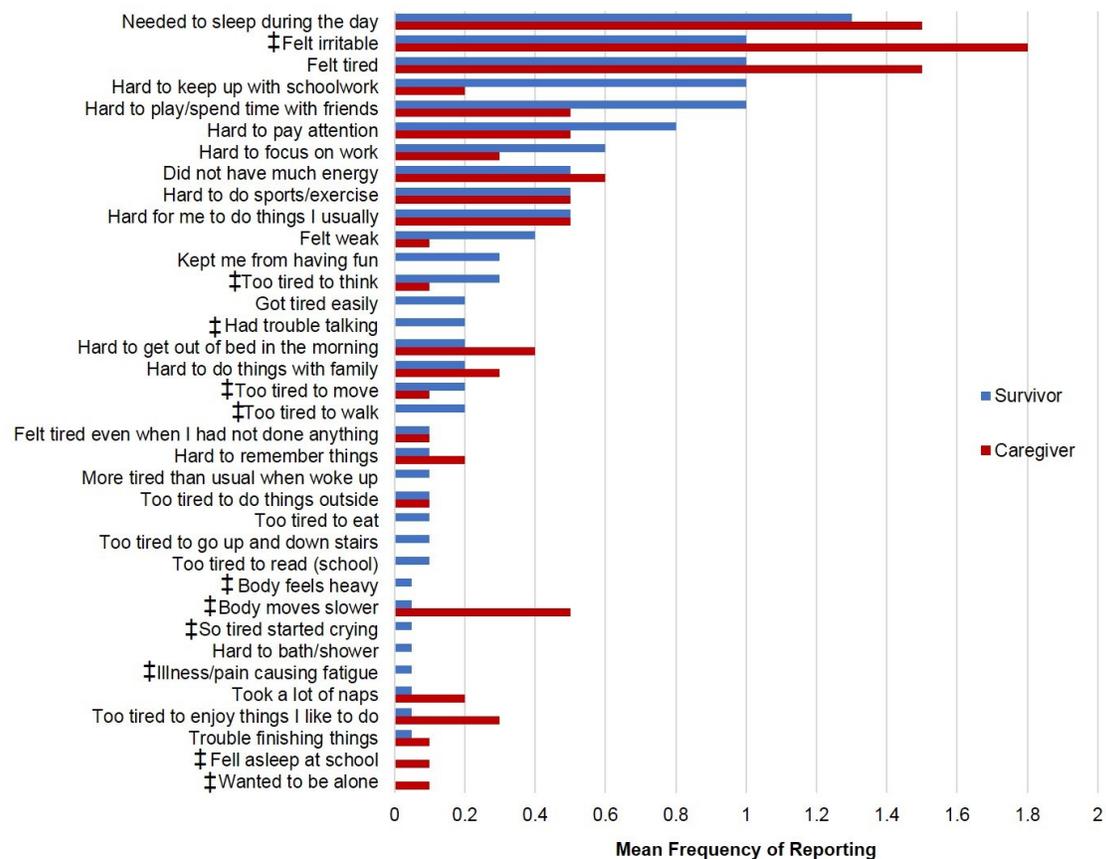
Supplementary Figure 1. Mean Frequency of Meaningful Concepts in Pain Interference Reported by Survivors and Caregivers[†]



[†] Survivors endorsed 79% of the items in the PROMIS pain interference banks/pools; caregivers endorsed 64.7% of banks/pools.

[‡] New concept generated from the semi-structured interviews.

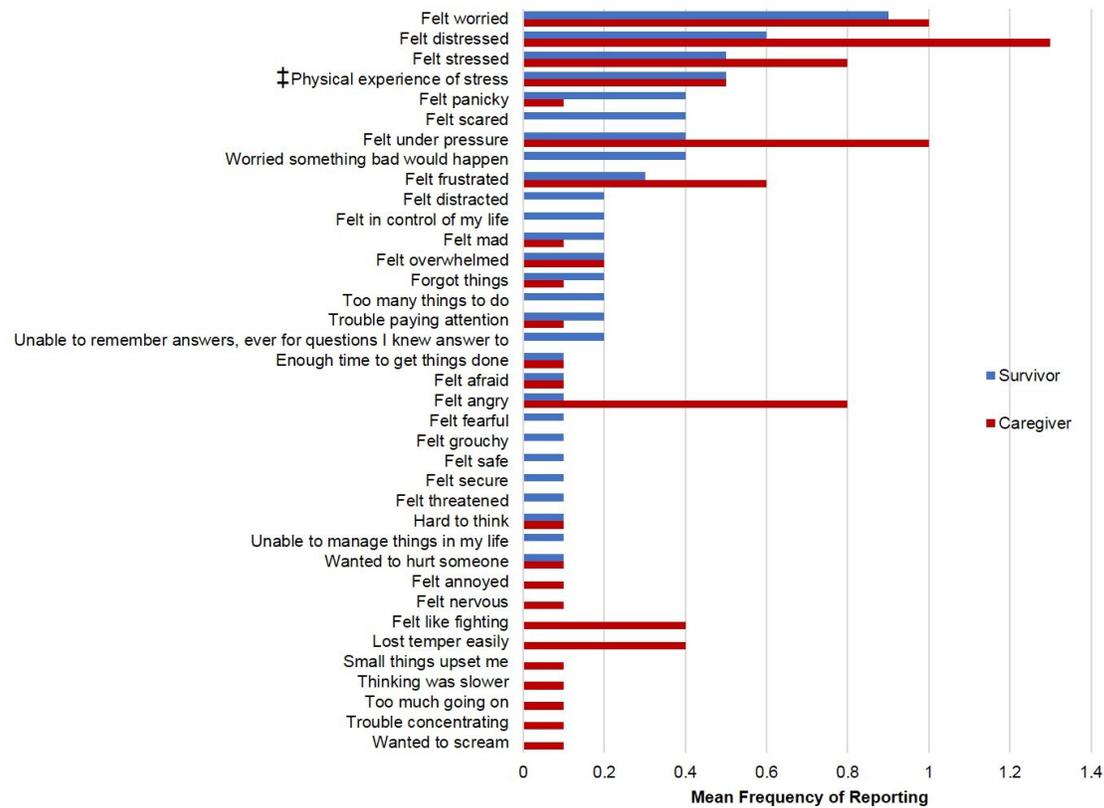
Supplementary Figure 2. Mean Frequency of Meaningful Concepts in Fatigue Reported by Survivors and Caregivers[†]



[†] Survivors endorsed 89.3% of the items in the PROMIS fatigue banks/pools; caregivers endorsed 64.3% of banks/pools.

[‡] New concept generated from the semi-structured interviews.

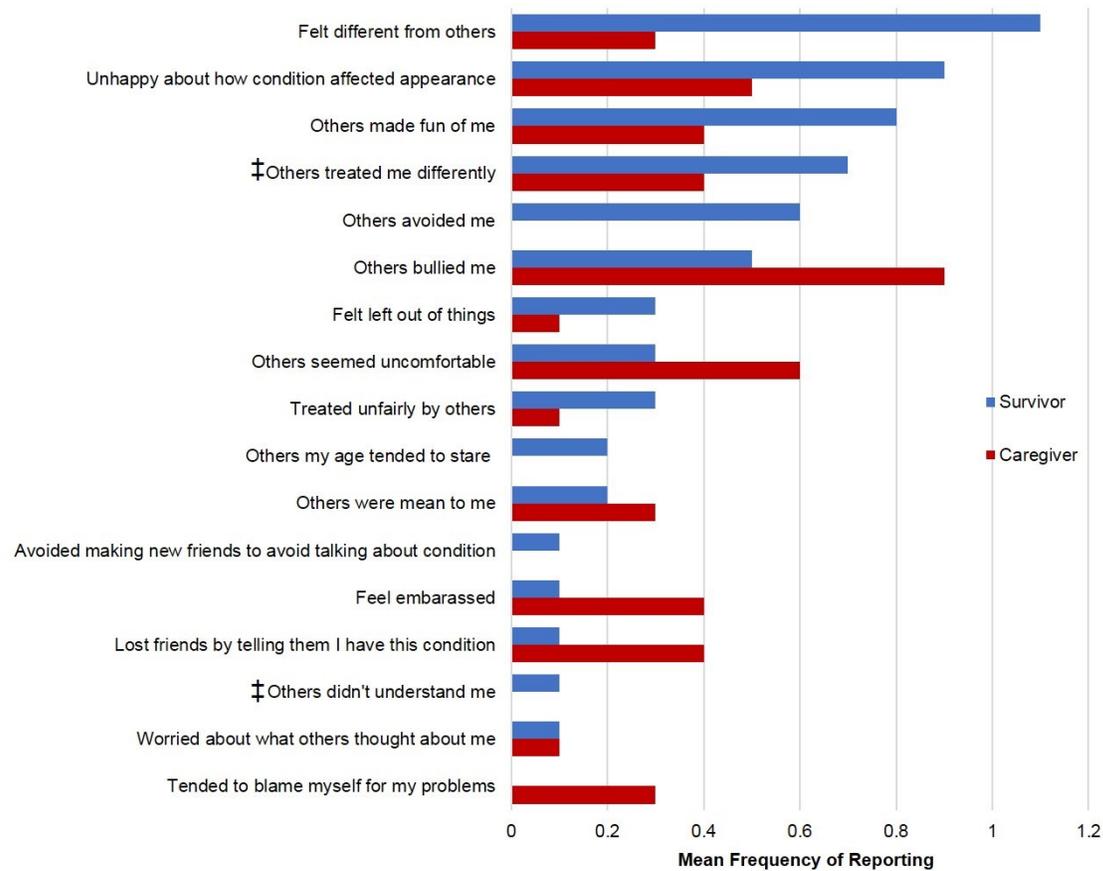
Supplementary Figure 3. Mean Frequency of Meaningful Concepts in Psychological Stress Reported by Survivors and Caregivers[†]



[†] Survivors endorsed 42.2% of the items in the PROMIS psychological stress banks/pools; caregivers endorsed 37.5% of banks/pools.

[‡] New concept generated from the semi-structure interviews.

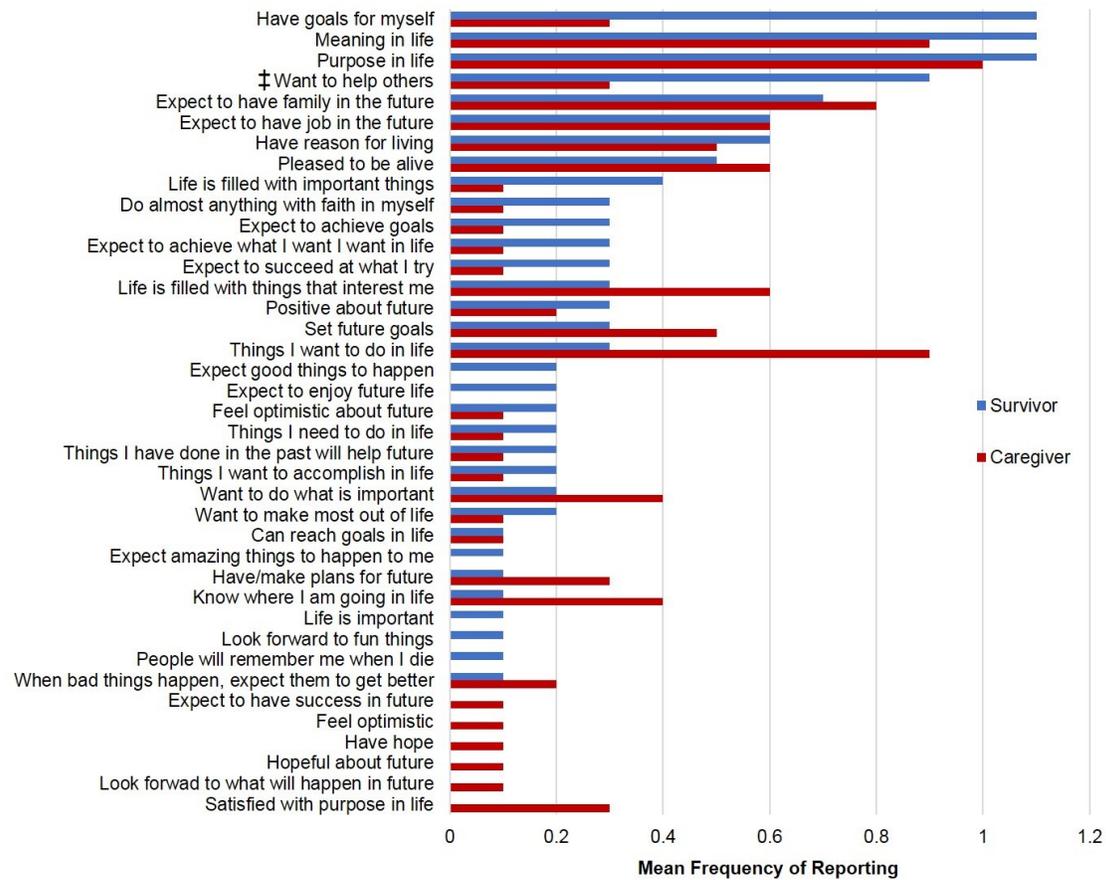
Supplementary Figure 4. Mean Frequency of Meaningful Concepts in Stigma Reported by Survivors and Caregivers[†]



[†] Survivors endorsed 70% of the items in the PROMIS stigma banks/pools; caregivers endorsed 60% of banks/pools.

[‡] New concept generated from the semi-structure interviews.

Supplementary Figure 5. Mean Frequency of Meaningful Concepts in Meaning and Purpose Reported by Survivors and Caregivers[†]



[†] Survivors endorsed 59.3% of the items in the PROMIS meaning and purpose banks/pools; caregivers endorsed 59.3% of banks/pools.

[‡] New concept generated from semi-structure interviews.