Supplementary Online Content


eAppendix. Study Questionnaires, Patient and Parent

This supplementary material has been provided by the authors to give readers additional information about their work.
Before we start

Your views are important to us. Please take as much time as you need and answer as accurately as possible. You can skip any questions that you do not want to answer and can stop the survey at any point. If you have any questions or you don’t understand something in this survey please let me know.

Part 1: A few questions about you:

* Interviewer record: Patient’s Gender

- [ ] Female
- [ ] Male

1. How old are you?

   ________ years old

2. What grade level did you last complete?

   __________________________________________

3. Do you consider yourself:

   Please check all the boxes that apply

   - [ ] American Indian or Alaska Native
   - [ ] Asian or Indian
   - [ ] Black or African American
   - [ ] Hispanic, Latino or Spanish origin
   - [ ] Native Hawaiian or Pacific Islander
□ White
□ Other (please specify)____________________________________

4 One year from now do you think that your health will be:
□ A lot better
□ Somewhat better
□ The same
□ Somewhat worse
□ A lot worse

5 Overall, what would you say that your current quality of life is? By quality of life we mean the ability to participate in and enjoy your daily activities.
□ Excellent (able to participate in and enjoy all of your daily activities)
□ Very good (able to participate in and enjoy most of your daily activities)
□ Good (able to participate in and enjoy some of your daily activities)
□ Fair (able to participate in and enjoy few of your daily activities)
□ Poor (able to participate in and enjoy none of your daily activities)

Part 2: A few questions about your illness:

6 What type of cancer do you have?
____________________________________
7 What has your doctor told you about the chances of a child with your type of cancer being cured, where being cured means not having cancer anymore?

☐ Chance of cure is very high
☐ Chance of cure is somewhat high
☐ Chance of cure is not high
☐ My doctor has not discussed the chance of cure with me
☐ Unsure

8 What do you believe the chances are that you will be cured?

☐ Chance of cure is very high
☐ Chance of cure is somewhat high
☐ Chance of cure is not high
☐ Don't Know

9 What do your parents believe are the chances that you will be cured?

☐ Chance of cure is very high
☐ Chance of cure is somewhat high
☐ Chance of cure is not high
☐ My parents do not know what the chance of cure may be
☐ I don’t know what my parents believe about the chance of cure
10 How much do you talk with your parents about your illness?

☐ A great deal
☐ A moderate amount
☐ Some
☐ A little bit
☐ Not at all

11 Would you say that talking with your parents about your illness is:

☐ Very Easy
☐ Somewhat Easy
☐ Somewhat Difficult
☐ Very Difficult
☐ Unsure
12 Before starting cancer treatment, did your parents or doctors discuss with you how the cancer treatments might make you feel physically?

☐ Yes, a lot
☐ Yes, a moderate amount
☐ Yes, a little
☐ No

13 Before starting cancer treatment, did your parents or doctors discuss with you how the cancer treatments might make you feel emotionally?

☐ Yes, a lot
☐ Yes, a moderate amount
☐ Yes, a little
☐ No

14 Before starting cancer treatment, did your parents or doctors discuss with you how the cancer treatments might affect your quality of life? By quality of life we mean the ability to participate in and enjoy your daily activities.

☐ Yes, a lot
☐ Yes, a moderate amount
☐ Yes, a little
☐ No
15 How important to you are the following factors when deciding which treatment a child will get for his/her cancer after he/she is first diagnosed?

<table>
<thead>
<tr>
<th>Chance of cure</th>
<th>Ability to participate/enjoy daily activities</th>
<th>Side effects</th>
<th>Amount of time spent at the hospital</th>
<th>Total length of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Very important</td>
<td>□ Very important</td>
<td>□ Very important</td>
<td>□ Very important</td>
<td>□ Very important</td>
</tr>
<tr>
<td>□ Somewhat important</td>
<td>□ Somewhat important</td>
<td>□ Somewhat important</td>
<td>□ Somewhat important</td>
<td>□ Somewhat important</td>
</tr>
<tr>
<td>□ A little important</td>
<td>□ A little important</td>
<td>□ A little important</td>
<td>□ A little important</td>
<td>□ A little important</td>
</tr>
<tr>
<td>□ Not important at all</td>
<td>□ Not important at all</td>
<td>□ Not important at all</td>
<td>□ Not important at all</td>
<td>□ Not important at all</td>
</tr>
<tr>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
</tr>
</tbody>
</table>
Part 3: Symptoms

Note: The questions in this section ask about your symptoms in the first month after you started cancer treatment.

16 What was the highest level of pain you had in the first month after you started cancer treatment?

*Please choose a number from 0-10, where 0 is no pain and 10 is the worst pain you can imagine*

0 1 2 3 4 5 6 7 8 9 10
None---------------------------------------→Worst Imaginable

If answer is 0=no pain then go to # 19

17 In the first month after you started cancer treatment, how much did you suffer as a result of your pain?

☐ Suffered a great deal
☐ Suffered a lot
☐ Suffered a moderate amount
☐ Suffered a little
☐ Did not suffer at all
☐ Unsure / Don't Know
☐ I did not have pain
18  A. Overall, in the first month after you started cancer treatment, how much did your oncology care team try to treat your pain? By oncology care team I mean the group of doctors, nurses, social workers, therapists, and other medical providers who help care for you.

☐ They tried a lot
☐ They tried a moderate amount
☐ They tried a little
☐ They did not try
☐ I did not have pain

B. If you got treatment for your pain, how well did the treatment control your pain? It was:

☐ Well controlled
☐ Moderately controlled
☐ A little controlled
☐ Not controlled at all
☐ Unsure
☐ I did not get treated for pain
Interviewer: If the participant’s response to question #19 is “I did not have ____” for a particular symptom, please cross out that symptom and omit in questions #20-21.

19 In the first month after you started cancer treatment, how much did you suffer as a result of the following symptoms?

<table>
<thead>
<tr>
<th>Nausea</th>
<th>Loss of Appetite</th>
<th>Diarrhea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
</tr>
<tr>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
</tr>
<tr>
<td>Suffered a moderate amount</td>
<td>Suffered a moderate amount</td>
<td>Suffered a moderate amount</td>
</tr>
<tr>
<td>Suffered a little</td>
<td>Suffered a little</td>
<td>Suffered a little</td>
</tr>
<tr>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>I did not have nausea</td>
<td>I did not have loss of appetite</td>
<td>I did not have diarrhea</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Constipation</th>
<th>Anxiety/Nervousness</th>
<th>Depression/Sadness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
</tr>
<tr>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
</tr>
<tr>
<td>Suffered a moderate amount</td>
<td>Suffered a moderate amount</td>
<td>Suffered a moderate amount</td>
</tr>
<tr>
<td>Suffered a little</td>
<td>Suffered a little</td>
<td>Suffered a little</td>
</tr>
<tr>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>I did not have constipation</td>
<td>I did not have anxiety / nervousness</td>
<td>I did not have depression / sadness</td>
</tr>
</tbody>
</table>
20 Overall, in the first month after you started cancer treatment, how much did your oncology care team try to treat the following symptoms? By oncology care team I mean the group of doctors, nurses, social workers, therapists, and other medical providers who help care for you.

<table>
<thead>
<tr>
<th>Nausea</th>
<th>Loss of Appetite</th>
<th>Diarrhea</th>
</tr>
</thead>
<tbody>
<tr>
<td>They tried a lot</td>
<td>They tried a lot</td>
<td>They tried a lot</td>
</tr>
<tr>
<td>They tried a moderate amount</td>
<td>They tried a moderate amount</td>
<td>They tried a moderate amount</td>
</tr>
<tr>
<td>They tried a little</td>
<td>They tried a little</td>
<td>They tried a little</td>
</tr>
<tr>
<td>They did not try</td>
<td>They did not try</td>
<td>They did not try</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>I did not have nausea</td>
<td>I did not have loss of appetite</td>
<td>I did not have diarrhea</td>
</tr>
</tbody>
</table>

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</thead>
<tbody>
<tr>
<td>They tried a lot</td>
<td>They tried a lot</td>
<td>They tried a lot</td>
</tr>
<tr>
<td>They tried a moderate amount</td>
<td>They tried a moderate amount</td>
<td>They tried a moderate amount</td>
</tr>
<tr>
<td>They tried a little</td>
<td>They tried a little</td>
<td>They tried a little</td>
</tr>
<tr>
<td>They did not try</td>
<td>They did not try</td>
<td>They did not try</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>I did not have constipation</td>
<td>I did not have anxiety / nervousness</td>
<td>I did not have depression / sadness</td>
</tr>
</tbody>
</table>
21 If you received treatment for the following symptoms in the first month after you started cancer treatment, overall how well did the treatment control your symptom?

<table>
<thead>
<tr>
<th>Nausea was:</th>
<th>Loss of Appetite was:</th>
<th>Diarrhea was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well controlled</td>
<td>Well controlled</td>
<td>Well controlled</td>
</tr>
<tr>
<td>Moderately controlled</td>
<td>Moderately controlled</td>
<td>Moderately controlled</td>
</tr>
<tr>
<td>A little controlled</td>
<td>A little controlled</td>
<td>A little controlled</td>
</tr>
<tr>
<td>Not controlled at all</td>
<td>Not controlled at all</td>
<td>Not controlled at all</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>I did not get treated for nausea</td>
<td>I did not get treated for loss of appetite</td>
<td>I did not get treated for diarrhea</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Constipation was:</th>
<th>Anxiety/Nervousness was:</th>
<th>Depression/Sadness was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well controlled</td>
<td>Well controlled</td>
<td>Well controlled</td>
</tr>
<tr>
<td>Moderately controlled</td>
<td>Moderately controlled</td>
<td>Moderately controlled</td>
</tr>
<tr>
<td>A little controlled</td>
<td>A little controlled</td>
<td>A little controlled</td>
</tr>
<tr>
<td>Not controlled at all</td>
<td>Not controlled at all</td>
<td>Not controlled at all</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>I did not get treated for constipation</td>
<td>I did not get treated for anxiety / nervousness</td>
<td>I did not get treated for depression / sadness</td>
</tr>
</tbody>
</table>
22 Suppose that you could choose between two treatments for your cancer.

TREATMENT A: has an 80% chance of cure and leads to side effects such as nausea/vomiting, diarrhea and pain.

TREATMENT B: has a 75% chance of cure and has significantly fewer side effects and you would have better quality of life during treatment as compared to treatment A.

Would you say that you would:

☐ Definitely choose treatment A

☐ Probably choose treatment A

☐ Probably choose treatment B

☐ Definitely choose treatment B

☐ Unsure

23 Again, suppose that you could choose between two treatments for your cancer.

TREATMENT A: has a 65% chance of cure and has significantly fewer side effects and you would have better quality of life during treatment as compared to treatment B.

TREATMENT B: has an 80% chance of cure and leads to side effects such as nausea/vomiting, diarrhea and pain.

Would you say that you would:

☐ Definitely choose treatment A

☐ Probably choose treatment A

☐ Probably choose treatment B

☐ Definitely choose treatment B

☐ Unsure
Part 4: Your Views

24 In general, how much do you think children’s oncology care teams should focus on a child’s quality of life, or a child’s ability to participate in and enjoy his/her daily activities, beginning in the first month of cancer treatment? By oncology care teams I mean the group of doctors, nurses, social workers, therapists, and other medical providers who help care for children with cancer.

☐ A great deal
☐ A lot
☐ A moderate amount
☐ A little
☐ Not at all
☐ Unsure

25 In the first month of cancer treatment, was the amount that your oncology care team focused on your quality of life, or your ability to participate in and enjoy your daily activities:

☐ Too much
☐ Just right
☐ Not enough
☐ Unsure
26 What things do you wish that the members of your oncology care team had discussed with you more or given you more information about?

Please check all the boxes that apply

☐ How to treat your pain

☐ How to treat your physical symptoms
  (such as nausea/vomiting, diarrhea/constipation, loss of appetite)

☐ How to treat your emotional symptoms (such as depression, anxiety)

☐ The impact of cancer and its treatment on your daily activities

☐ The impact of cancer and its treatment on your family life

☐ How available cancer treatments differ in the ways they affect your quality of life

☐ The impact of cancer and its treatment on your quality of life after cancer treatment

☐ The possibility of a child not being cured of his/her cancer

☐ Fears and hope about your illness

☐ Religious or spiritual issues

☐ Other (please specify): ________________________________
  __________________________________________________
  __________________________________________________
  __________________________________________________
  __________________________________________________
27 Have you heard of the term “palliative care”?

☐ No (if no go to # 30)

☐ Yes: What does palliative care mean to you?

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

28 Do you have any personal experience with palliative care?

☐ No

☐ Yes: Please describe your experience:

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

29 In general, what is your attitude toward palliative care?

☐ Positive attitude

Please explain why you have a positive attitude toward palliative care:

__________________________________________________________________

__________________________________________________________________

☐ Neutral attitude (Not positive or negative)

☐ Negative attitude

Please explain why you have a negative attitude toward palliative care:

__________________________________________________________________

__________________________________________________________________

☐ Unsure
30 The palliative care team is a group of experts in treating patients’ symptoms and improving patients’ quality of life. Would you say that including the palliative care team in your care around the time that you were first diagnosed with cancer would have:

Please check all the boxes that apply

☐ Been helpful for treating your symptoms
☐ Helped with making initial treatment decisions
☐ Been a positive addition to your overall care
☐ Gotten in the way of your relationship with your oncology doctor/care team
☐ Taken away from your hope that you would be cured
☐ Interfered with your cancer therapy
☐ Unsure

31 Some people want to meet with the palliative care team, which is a group of experts in treating patients’ symptoms and improving patients’ quality of life, around the time of diagnosis while others do not. Would you say that you would:

☐ Definitely want to have met with the palliative care team
☐ Probably want to have met with the palliative care team
☐ Probably not want to have met with the palliative care team
☐ Definitely not want to have met with the palliative care team
☐ Unsure

Please explain why you would or would not want to have met with the palliative care team:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
32 The palliative care team provides care for patients at all stages of illness, including end of life care for dying patients. How would the fact that the palliative care team also provides end of life care affect your willingness to meet with them around the time that you were first diagnosed?

- [ ] It would make you *more* willing to meet with the palliative care team
- [ ] It would *not change* your willingness to meet with the palliative care team
- [ ] It would make you *less* willing to meet with the palliative care team
- [ ] Unsure

33 In general, when would you recommend that a palliative care team get involved in the care of a child with cancer:

*Please check all the boxes that apply*

- [ ] At the beginning of cancer therapy
- [ ] If pain or symptom management is a problem
- [ ] If the cancer gets worse or comes back
- [ ] At the end of life
- [ ] Throughout all of a child’s cancer care
- [ ] They should not be involved in a child’s cancer care
- [ ] Unsure
Part 7: Your Feedback

34 Would you say that answering the questions in this survey was:

☐ Very helpful

☐ Somewhat helpful

☐ A little helpful

☐ Not helpful at all

35 Would you say that answering the questions in this survey was:

☐ Very upsetting

☐ Somewhat upsetting

☐ A little upsetting

☐ Not upsetting at all
36 Overall, do you feel that taking this survey was a good or bad experience?

☐ Very good

☐ Somewhat good

☐ Neutral, meaning not good or bad

☐ Somewhat bad

☐ Very bad

Thank you for answering our questions. Your answers are very valuable to us as we try to improve care for all children with cancer.

If you are feeling anxious or upset, or if you have any questions about this survey, you should talk to the person who gave you the survey. You also can talk to the person in charge of the study at St. Jude Children’s Research Hospital, Dr. Deena Levine, at 901.595.8149 or Deena.Levine@stjude.org.

Thank You!
Evaluating Supportive Care for Children with Cancer: A Multi-Institutional Survey Study of Pediatric Oncology Patients and Parents - - PARENT

Before you start

Your views are important to us. Please take as much time as you need and answer as accurately as possible. If you have any questions, please talk to the person who gave you this survey. You can skip any questions that you do not want to answer and can stop the survey at any point.

To answer a question, mark an X or √ in the box that best matches your view. If a question asks you to write your answer, please try to write clearly.

Please check only one box per question, unless the question asks you to check all the boxes that apply.

Part 1: A few questions about you and your child:

1  Are you male or female?
   ☐ Male
   ☐ Female

2  What is your relationship to the patient?
   ☐ Biological Parent
   ☐ Step-parent
   ☐ Adoptive Parent
   ☐ Grandparent
   ☐ Other: (please specify)________________________________________
3  How old are you?

_________ years old

4  Are you currently:

☐ Single, never married
☐ Married
☐ Partnered
☐Separated
☐ Divorced
☐ Widowed

5  Who does your child live with? Please check all the boxes that apply

☐ Mother
☐ Father
☐Sisters/Brothers
☐ Grandparent
☐ Step-parent
☐ Other: (please specify)______________________________
6  **Do you consider yourself:**  *Please check all the boxes that apply*

- American Indian or Alaska Native
- Asian or Indian
- Black or African American
- Hispanic, Latino or Spanish origin
- Native Hawaiian or Pacific Islander
- White
- Other (please specify)________________________

7  **Please check the highest level of education that you have completed.**

- I completed graduate school
- I completed college
- I completed high school
- I completed grade school
- I did not complete grade school

8  **Last year, what was the total income in your household before taxes?**

- Under $25,000
- $25,000 - $49,999
- $50,000 - $99,999
- $100,000 - $249,999
- More than $250,000
9  Would you say YOUR current overall health is:

☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

10  Would you say that YOUR CHILD’S current quality of life is?  By quality of life we mean your child’s ability to participate in and enjoy his/her daily activities.

☐ Excellent (able to participate in and enjoy all of his/her daily activities)
☐ Very good (able to participate in and enjoy most of his/her daily activities)
☐ Good (able to participate in and enjoy some of his/her daily activities)
☐ Fair (able to participate in and enjoy few of his/her daily activities)
☐ Poor (able to participate in and enjoy none of his/her daily activities)

11  One year from now, do you think YOUR CHILD’S overall health will be:

☐ A lot better
☐ Somewhat better
☐ The same
☐ Somewhat worse
☐ A lot worse
Part 2: A few questions about your child’s illness:

12 When was your child first diagnosed with cancer?

___________________________(month/year)

13 What type of cancer was your child diagnosed with?

____________________________

14 What has your child’s doctor told you about the chances of a child with this type of cancer being cured (being cured means not having cancer any more)?

☐ My child’s doctor has not discussed the chance of a cure with me

☐ Chance of cure is very high

☐ Chance of cure is somewhat high

☐ Chance of cure is not high

☐ Unsure

15 What do you believe the chances are that your child will be cured?

☐ Chance of cure is very high

☐ Chance of cure is somewhat high

☐ Chance of cure is not high

☐ Don’t Know
16 What do you think your child believes are the chances that he/she will be cured?

- [ ] Chance of cure is very high
- [ ] Chance of cure is somewhat high
- [ ] Chance of cure is not high
- [ ] My child does not know what his/her chance of cure may be
- [ ] I don’t know what my child believes about his/her chance of cure

17 How much would you say that you talk with your child about his/her illness?

- [ ] A great deal
- [ ] A moderate amount
- [ ] Some
- [ ] A little bit
- [ ] Not at all

18 Would you say that talking with your child about his/her illness is:

- [ ] Very Easy
- [ ] Somewhat Easy
- [ ] Somewhat Difficult
- [ ] Very Difficult
- [ ] Unsure
19 Before starting cancer treatment, did your child’s doctors discuss with you how the cancer treatments might make your child feel physically?

- Yes, a lot
- Yes, a moderate amount
- Yes, a little
- No

20 Before starting cancer treatment, did your child’s doctors discuss with you how the cancer treatments might make your child feel emotionally?

- Yes, a lot
- Yes, a moderate amount
- Yes, a little
- No

21 Before starting cancer treatment, did your child’s doctors discuss with you how the cancer treatments might affect your child’s quality of life. By quality of life we mean your child’s ability to participate in and enjoy his/her daily activities?

- Yes, a lot
- Yes, a moderate amount
- Yes, a little
- No
22. How important to you were the following factors in deciding which cancer treatments your child received after he/she was first diagnosed?

<table>
<thead>
<tr>
<th>Chance of cure</th>
<th>Ability to participate/enjoy daily activities</th>
<th>Side effects</th>
<th>Amount of time spent at the hospital</th>
<th>Total length of treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Very important</td>
<td>□ Very important</td>
<td>□ Very important</td>
<td>□ Very important</td>
</tr>
<tr>
<td></td>
<td>□ Somewhat important</td>
<td>□ Somewhat important</td>
<td>□ Somewhat important</td>
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<td></td>
<td>□ A little important</td>
<td>□ A little important</td>
<td>□ A little important</td>
<td>□ A little important</td>
</tr>
<tr>
<td></td>
<td>□ Not important at all</td>
<td>□ Not important at all</td>
<td>□ Not important at all</td>
<td>□ Not important at all</td>
</tr>
<tr>
<td></td>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
</tr>
</tbody>
</table>

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Part 3: Symptoms

Note: The questions in this section ask about your child’s symptoms in the first month after he/she started cancer treatment.

23 What was your child’s highest level of pain in the first month after he/she started cancer treatment?

Please Circle the number that matches the level of pain best, where on a scale of 0-10, 0 is no pain and 10 is the worst pain you can imagine, or circle don’t know

0 1 2 3 4 5 6 7 8 9 10

Don’t Know

24 In the first month after your child started cancer treatment, how much did he/she suffer as a result of pain?

☐ Suffered a great deal
☐ Suffered a lot
☐ Suffered a moderate amount
☐ Suffered a little
☐ Did not suffer at all
☐ My child did not have pain (go to question #26)
☐ Unsure / Don’t Know
25 A. Overall, in the first month after your child started cancer treatment, how much did his/her oncology care team try to treat your child’s pain? By oncology care team we mean the group of doctors, nurses, social workers, therapists, and other medical providers who help care for your child.

☐ They tried a lot
☐ They tried a moderate amount
☐ They tried a little
☐ They did not try
☐ My child did not have pain

B. If your child was treated for his/her pain, how well did the treatment control the pain? It was:

☐ Well controlled
☐ Moderately controlled
☐ A little controlled
☐ Not controlled at all
☐ Unsure
☐ My child did not get treated for pain
☐ My child did not have pain
In the first month after your child started cancer treatment, how much did he/she suffer as a result of the following symptoms?

<table>
<thead>
<tr>
<th>Nausea</th>
<th>Loss of Appetite</th>
<th>Diarrhea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
</tr>
<tr>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
</tr>
<tr>
<td>Suffered a moderate</td>
<td>Suffered a moderate</td>
<td>Suffered a moderate</td>
</tr>
<tr>
<td>amount</td>
<td>amount</td>
<td>amount</td>
</tr>
<tr>
<td>Suffered a little</td>
<td>Suffered a little</td>
<td>Suffered a little</td>
</tr>
<tr>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>My child did not have</td>
<td>My child did not have loss of appetite</td>
<td>My child did not have diarrhea</td>
</tr>
<tr>
<td>nausea</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Constipation</th>
<th>Anxiety/Nervousness</th>
<th>Depression/Sadness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
<td>Suffered a great deal</td>
</tr>
<tr>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
<td>Suffered a lot</td>
</tr>
<tr>
<td>Suffered a moderate</td>
<td>Suffered a moderate</td>
<td>Suffered a moderate</td>
</tr>
<tr>
<td>amount</td>
<td>amount</td>
<td>amount</td>
</tr>
<tr>
<td>Suffered a little</td>
<td>Suffered a little</td>
<td>Suffered a little</td>
</tr>
<tr>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
<td>Did not suffer at all</td>
</tr>
<tr>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td>My child did not have</td>
<td>My child did not have anxiety/nervousness</td>
<td>My child did not have depression/sadness</td>
</tr>
<tr>
<td>constipation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
27 Overall, in the first month after your child started cancer treatment, how much did his/her oncology care team try to treat the following symptoms?

By oncology care team we mean the group of doctors, nurses, social workers, therapists, and other medical providers who help care for your child.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Nausea</th>
<th>Loss of Appetite</th>
<th>Diarrhea</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ They tried a lot</td>
<td>□ They tried a lot</td>
<td>□ They tried a lot</td>
</tr>
<tr>
<td></td>
<td>□ They tried a moderate amount</td>
<td>□ They tried a moderate amount</td>
<td>□ They tried a moderate amount</td>
</tr>
<tr>
<td></td>
<td>□ They tried a little</td>
<td>□ They tried a little</td>
<td>□ They tried a little</td>
</tr>
<tr>
<td></td>
<td>□ They did not try</td>
<td>□ They did not try</td>
<td>□ They did not try</td>
</tr>
<tr>
<td></td>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
</tr>
<tr>
<td></td>
<td>□ My child did not have nausea</td>
<td>□ My child did not have nausea</td>
<td>□ My child did not have diarrhea</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Constipation</th>
<th>Anxiety/Nervousness</th>
<th>Depression/Sadness</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ They tried a lot</td>
<td>□ They tried a lot</td>
<td>□ They tried a lot</td>
</tr>
<tr>
<td></td>
<td>□ They tried a moderate amount</td>
<td>□ They tried a moderate amount</td>
<td>□ They tried a moderate amount</td>
</tr>
<tr>
<td></td>
<td>□ They tried a little</td>
<td>□ They tried a little</td>
<td>□ They tried a little</td>
</tr>
<tr>
<td></td>
<td>□ They did not try</td>
<td>□ They did not try</td>
<td>□ They did not try</td>
</tr>
<tr>
<td></td>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
</tr>
<tr>
<td></td>
<td>□ My child did not have constipation</td>
<td>□ My child did not have anxiety / nervousness</td>
<td>□ My child did not have depression / sadness</td>
</tr>
</tbody>
</table>
If your child received treatment for the following symptoms in the first month after he/she started cancer treatment, overall how well did the treatment control your child’s symptom?

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Control Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea</td>
<td>Well controlled, Moderately controlled, A little controlled, Not controlled at all, Unsure, My child did not get treated for nausea</td>
</tr>
<tr>
<td>Loss of Appetite</td>
<td>Well controlled, Moderately controlled, A little controlled, Not controlled at all, Unsure, My child did not get treated for loss of appetite</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>Well controlled, Moderately controlled, A little controlled, Not controlled at all, Unsure, My child did not get treated for diarrhea</td>
</tr>
<tr>
<td>Constipation</td>
<td>Well controlled, Moderately controlled, A little controlled, Not controlled at all, Unsure, My child did not get treated for constipation</td>
</tr>
<tr>
<td>Anxiety/Nervousness</td>
<td>Well controlled, Moderately controlled, A little controlled, Not controlled at all, Unsure, My child did not get treated for anxiety / nervousness</td>
</tr>
<tr>
<td>Depression/Sadness</td>
<td>Well controlled, Moderately controlled, A little controlled, Not controlled at all, Unsure, My child did not get treated for depression / sadness</td>
</tr>
</tbody>
</table>
Overall, in the first month after your child started cancer treatment, how much did his/her oncology care team try to treat the following symptoms?

By oncology care team we mean the group of doctors, nurses, social workers, therapists, and other medical providers who help care for your child.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Nausea</th>
<th>Loss of Appetite</th>
<th>Diarrhea</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>They tried a lot</td>
<td>They tried a lot</td>
<td>They tried a lot</td>
</tr>
<tr>
<td></td>
<td>They tried a moderate amount</td>
<td>They tried a moderate amount</td>
<td>They tried a moderate amount</td>
</tr>
<tr>
<td></td>
<td>They tried a little</td>
<td>They tried a little</td>
<td>They tried a little</td>
</tr>
<tr>
<td></td>
<td>They did not try</td>
<td>They did not try</td>
<td>They did not try</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td></td>
<td>My child did not have nausea</td>
<td>My child did not have loss of appetite</td>
<td>My child did not have diarrhea</td>
</tr>
<tr>
<td>Constipation</td>
<td>They tried a lot</td>
<td>They tried a lot</td>
<td>They tried a lot</td>
</tr>
<tr>
<td></td>
<td>They tried a moderate amount</td>
<td>They tried a moderate amount</td>
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</tr>
<tr>
<td></td>
<td>They tried a little</td>
<td>They tried a little</td>
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<tr>
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<td>They did not try</td>
<td>They did not try</td>
<td>They did not try</td>
</tr>
<tr>
<td></td>
<td>Unsure</td>
<td>Unsure</td>
<td>Unsure</td>
</tr>
<tr>
<td></td>
<td>My child did not have constipation</td>
<td>My child did not have anxiety / nervousness</td>
<td>My child did not have depression / sadness</td>
</tr>
</tbody>
</table>

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If your child received treatment for the following symptoms in the first month after he/she started cancer treatment, overall how well did the treatment control your child’s symptom?

<table>
<thead>
<tr>
<th>Nausea was:</th>
<th>Loss of Appetite was:</th>
<th>Diarrhea was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Well controlled</td>
<td>□ Well controlled</td>
<td>□ Well controlled</td>
</tr>
<tr>
<td>□ Moderately controlled</td>
<td>□ Moderately controlled</td>
<td>□ Moderately controlled</td>
</tr>
<tr>
<td>□ A little controlled</td>
<td>□ A little controlled</td>
<td>□ A little controlled</td>
</tr>
<tr>
<td>□ Not controlled at all</td>
<td>□ Not controlled at all</td>
<td>□ Not controlled at all</td>
</tr>
<tr>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
</tr>
<tr>
<td>□ My child did not get treated for nausea</td>
<td>□ My child did not get treated for loss of appetite</td>
<td>□ My child did not get treated for diarrhea</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Constipation was:</th>
<th>Anxiety/Nervousness was:</th>
<th>Depression/Sadness was:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Well controlled</td>
<td>□ Well controlled</td>
<td>□ Well controlled</td>
</tr>
<tr>
<td>□ Moderately controlled</td>
<td>□ Moderately controlled</td>
<td>□ Moderately controlled</td>
</tr>
<tr>
<td>□ A little controlled</td>
<td>□ A little controlled</td>
<td>□ A little controlled</td>
</tr>
<tr>
<td>□ Not controlled at all</td>
<td>□ Not controlled at all</td>
<td>□ Not controlled at all</td>
</tr>
<tr>
<td>□ Unsure</td>
<td>□ Unsure</td>
<td>□ Unsure</td>
</tr>
<tr>
<td>□ My child did not get treated for constipation</td>
<td>□ My child did not get treated for anxiety / nervousness</td>
<td>□ My child did not get treated for depression / sadness</td>
</tr>
</tbody>
</table>
29 Suppose that you could choose between two treatments for your child’s cancer.

TREATMENT A: has an 80% chance of cure and leads to side effects such as nausea/vomiting, diarrhea and pain.

TREATMENT B: has a 75% chance of cure and has significantly fewer side effects and your child would have a better quality of life during treatment as compared to treatment A.

Would you say that you would:

- [ ] Definitely choose treatment A
- [ ] Probably choose treatment A
- [ ] Probably choose treatment B
- [ ] Definitely choose treatment B
- [ ] Unsure

30 Again, suppose that you could choose between two treatments for your child’s cancer.

TREATMENT A: has a 65% chance of cure and has significantly fewer side effects and your child would have a better quality of life during treatment as compared to treatment B.

TREATMENT B: has an 80% chance of cure and leads to side effects such as nausea/vomiting, diarrhea and pain.

Would you say that you would:

- [ ] Definitely choose treatment A
- [ ] Probably choose treatment A
- [ ] Probably choose treatment B
- [ ] Definitely choose treatment B
- [ ] Unsure
Part 4: Your Views

31 In general, how much do you think children’s oncology care teams should focus on a child’s quality of life (a child’s ability to participate in and enjoy his/her daily activities) beginning in the first month of cancer treatment?

By oncology care team we mean the group of doctors, nurses, social workers, therapists, and other medical providers who help care for your child

☐ A great deal
☐ A lot
☐ A moderate amount
☐ A little
☐ Not at all
☐ Unsure

32 In the first month of cancer treatment, was the amount that your child’s oncology care team focused on your child’s quality of life (your child’s ability to participate in and enjoy his/her daily activities):

☐ Too much
☐ Just right
☐ Not enough
☐ Unsure
33 Please tell us what things you wish that members of your child’s oncology care team had discussed with you more or given you more information about?

*Please check all the boxes that apply*

- [ ] How to treat your child’s pain
- [ ] How to treat your child’s physical symptoms (such as nausea/vomiting, diarrhea/constipation, loss of appetite)
- [ ] How to treat your child’s emotional symptoms (such as depression, anxiety)
- [ ] The impact of cancer and its treatment on a child’s daily activities
- [ ] The impact of cancer and its treatment on your family life
- [ ] How available cancer treatments differ in the ways they could affect your child’s quality of life
- [ ] The impact of cancer and its treatment on your child’s quality of life after cancer treatment
- [ ] The possibility of a child not being cured of his/her cancer
- [ ] Fears and hope about your child’s illness
- [ ] Religious or spiritual issues
- [ ] Other (please specify): ____________________________
  ____________________________
  ____________________________
Please tell us what things you wish that members of your child’s oncology care team had discussed with your child more or given your child more information about? Please check all the boxes that apply.

- [ ] How to treat your child’s pain
- [ ] How to treat your child’s physical symptoms (such as nausea/vomiting, diarrhea/constipation, loss of appetite)
- [ ] How to treat your child’s emotional symptoms (such as depression, anxiety)
- [ ] The impact of cancer and its treatment on a child’s daily activities
- [ ] The impact of cancer and its treatment on your family life
- [ ] How available cancer treatments differ in the ways they could affect your child’s quality of life
- [ ] The impact of cancer and its treatment on your child’s quality of life after cancer treatment
- [ ] The possibility of a child not being cured of his/her cancer
- [ ] Fears and hope about your child’s illness
- [ ] Religious or spiritual issues
- [ ] Other (please specify): ______________________________________________________________
  ______________________________________________________________
  ______________________________________________________________
  ______________________________________________________________
35 Have you heard of the term “palliative care”?
☐ No (go to question # 38)
☐ Yes: What does palliative care mean to you?
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

36 Do you have any personal experience with palliative care?
☐ No, I do not have personal experience with palliative care
☐ Yes: Please describe your experience:
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________

37 In general, what is your attitude toward palliative care?
☐ Positive attitude
   Please explain why you have a positive attitude toward palliative care:
__________________________________________________________________
__________________________________________________________________
☐ Neutral attitude (Not positive or negative)
☐ Negative attitude
   Please explain why you have a negative attitude toward palliative care:
__________________________________________________________________
__________________________________________________________________
☐ Unsure
38 The palliative care team is a group of experts in treating patients’ symptoms and improving patients’ quality of life. Would you say that including the palliative care team in your child’s care around the time that he/she was first diagnosed with cancer would have: Please check all the boxes that apply

- [ ] Been helpful for treating your child’s symptoms
- [ ] Helped with making initial treatment decisions
- [ ] Been a positive addition to your child’s overall care
- [ ] Gotten in the way of your relationship with your child’s oncology doctor/care team
- [ ] Taken away from your hope that your child would be cured
- [ ] Interfered with your child’s cancer therapy
- [ ] Unsure

39 Some people would want to meet with the palliative care team (a group of medical providers that specializes in treating patients’ symptoms and improving patients’ quality of life) around the time of diagnosis while others would not. Would you say that you would:

- [ ] Definitely want to have met with the palliative care team
- [ ] Probably want to have met with the palliative care team
- [ ] Probably not want to have met with the palliative care team
- [ ] Definitely not want to have met with the palliative care team
- [ ] Unsure

Please explain why you would or would not want to have met with the palliative care team:

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
40 The palliative care team provides care for patients at all stages of illness, including end of life care for dying patients. How would the fact that the palliative care team also provides end of life care affect your willingness to meet with them around the time that your child was first diagnosed?

☐ It would make you more willing to meet with the palliative care team
☐ It would not change your willingness to meet with the palliative care team
☐ It would make you less willing to meet with the palliative care team
☐ Unsure

41 In general, when would you recommend that a palliative care team get involved in the care of a child with cancer: Please check all the boxes that apply

☐ At the beginning of cancer therapy
☐ If pain or symptom management is a problem
☐ If the cancer gets worse or comes back
☐ At the end of life
☐ Throughout all of a child’s cancer care
☐ They should not be involved in a child’s cancer care
☐ Unsure
Part 7: Your Feedback

42 Would you say that answering the questions in this survey was:

☐ Very helpful

☐ Somewhat helpful

☐ A little helpful

☐ Not helpful at all

43 Would you say that answering the questions in this survey was:

☐ Very upsetting

☐ Somewhat upsetting

☐ A little upsetting

☐ Not upsetting at all
44 Overall, do you feel that taking this survey was a good or bad experience?

☐ Very good

☐ Somewhat good

☐ Neutral, meaning not good or bad

☐ Somewhat bad

☐ Very bad

Thank you for answering our questions. Your answers are very valuable to us as we try to improve care for all children with cancer.

If you are feeling anxious or upset, or if you have any questions about this survey, you should talk to the person who gave you the survey. You also can talk to the person in charge of the study here at St. Jude Children’s Research Hospital, Dr. Deena Levine, at 901. 595.8149 or Deena.Levine@stjude.org.

Thank You!

1