# PEDIATRIC INVENTORY FOR PARENTS

**Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle HOW OFTEN the event has occurred for you in the past 7 days, using the 5 point scale below. Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale. Please complete both columns for each item.**

| EVENT | HOW OFTEN? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often | HOW DIFFICULT? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely |
|---|---|---|
| 1. Difficulty sleeping | 1 2 3 4 5 | 1 2 3 4 5 |
| 2. Arguing with family member(s) | 1 2 3 4 5 | 1 2 3 4 5 |
| 3. Bringing my child to the clinic or hospital | 1 2 3 4 5 | 1 2 3 4 5 |
| 4. Learning upsetting news | 1 2 3 4 5 | 1 2 3 4 5 |
| 5. Being unable to go to work/job | 1 2 3 4 5 | 1 2 3 4 5 |
| 6. Seeing my child's mood change quickly | 1 2 3 4 5 | 1 2 3 4 5 |
| 7. Speaking with doctor | 1 2 3 4 5 | 1 2 3 4 5 |
| 8. Watching my child have trouble eating | 1 2 3 4 5 | 1 2 3 4 5 |
| 9. Waiting for my child's test results | 1 2 3 4 5 | 1 2 3 4 5 |
| 10. Having money/financial troubles | 1 2 3 4 5 | 1 2 3 4 5 |
| 11. Trying not to think about my family's difficulties | 1 2 3 4 5 | 1 2 3 4 5 |
| 12. Feeling confused about medical information | 1 2 3 4 5 | 1 2 3 4 5 |
| 13. Being with my child during medical procedures | 1 2 3 4 5 | 1 2 3 4 5 |
| 14. Knowing my child is hurting or in pain | 1 2 3 4 5 | 1 2 3 4 5 |
| 15. Trying to attend to the needs of other family members | 1 2 3 4 5 | 1 2 3 4 5 |
| 16. Seeing my child sad or scared | 1 2 3 4 5 | 1 2 3 4 5 |
| 17. Talking with the nurse | 1 2 3 4 5 | 1 2 3 4 5 |
| 18. Making decisions about medical care or medicines | 1 2 3 4 5 | 1 2 3 4 5 |
| 19. Thinking about my child being isolated from others | 1 2 3 4 5 | 1 2 3 4 5 |
| 20. Being far away from family and/or friends | 1 2 3 4 5 | 1 2 3 4 5 |
| 21. Feeling numb inside | 1 2 3 4 5 | 1 2 3 4 5 |
| 22. Disagreeing with a member of the health care team | 1 2 3 4 5 | 1 2 3 4 5 |

Randi Streisand, Ph.D.

| EVENT | HOW OFTEN? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often | HOW DIFFICULT? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely |
|---|---|---|
| 23. Helping my child with his/her hygiene needs | 1 2 3 4 5 | 1 2 3 4 5 |
| 24. Worrying about the long term impact of the illness | 1 2 3 4 5 | 1 2 3 4 5 |
| 25. Having little time to take care of my own needs | 1 2 3 4 5 | 1 2 3 4 5 |
| 26. Feeling helpless over my child's condition | 1 2 3 4 5 | 1 2 3 4 5 |
| 27. Feeling misunderstood by family/friends as to the severity of my child's illness | 1 2 3 4 5 | 1 2 3 4 5 |
| 28. Handling changes in my child's daily medical routines | 1 2 3 4 5 | 1 2 3 4 5 |
| 29. Feeling uncertain about the future | 1 2 3 4 5 | 1 2 3 4 5 |
| 30. Being in the hospital over weekends/holidays | 1 2 3 4 5 | 1 2 3 4 5 |
| 31. Thinking about other children who have been seriously ill | 1 2 3 4 5 | 1 2 3 4 5 |
| 32. Speaking with my child about his/her illness | 1 2 3 4 5 | 1 2 3 4 5 |
| 33. Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing) | 1 2 3 4 5 | 1 2 3 4 5 |
| 34. Having my heart beat fast, sweating, or feeling tingly | 1 2 3 4 5 | 1 2 3 4 5 |
| 35. Feeling uncertain about disciplining my child | 1 2 3 4 5 | 1 2 3 4 5 |
| 36. Feeling scared that my child could get very sick or die | 1 2 3 4 5 | 1 2 3 4 5 |
| 37. Speaking with family members about my child's illness | 1 2 3 4 5 | 1 2 3 4 5 |
| 38. Watching my child during medical visits/procedures | 1 2 3 4 5 | 1 2 3 4 5 |
| 39. Missing important events in the lives of other family members | 1 2 3 4 5 | 1 2 3 4 5 |
| 40. Worrying about how friends and relatives interact with my child | 1 2 3 4 5 | 1 2 3 4 5 |
| 41. Noticing a change in my relationship with my partner | 1 2 3 4 5 | 1 2 3 4 5 |
| 42. Spending a great deal of time in unfamiliar settings | 1 2 3 4 5 | 1 2 3 4 5 |

Communication
Emotional distress
Medical care
Role function

} Frequency + Difficulty ? Totals

Randi Streisand, Ph.D.

ID# _____

Date:_____

# PedsQL™

## Stem Cell Transplant Module

Version 1.0

**PARENT REPORT** for **TODDLERS** (ages **2-4**)



**DIRECTIONS**

Children who have had a transplant sometimes have special problems. Please tell us **how much of** a problem each one has been for **your child** during the **past ONE month** by circling:

**0** if it is never a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has this been for **your child**…*

| **PAIN AND HURT** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Pain in muscles and/or joints | 0 | 1 | 2 | 3 | 4 |
| 2. Pain | 0 | 1 | 2 | 3 | 4 |
| Pain in…<br><br>(please indicate where your child has pain) | | | | | |

| **FATIGUE AND SLEEP** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling tired | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling physically weak | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty sleeping through the night | 0 | 1 | 2 | 3 | 4 |
| 4. Having to sleep a lot | 0 | 1 | 2 | 3 | 4 |
| 5. Feeling too tired to do things that he/she likes to do | 0 | 1 | 2 | 3 | 4 |

| **NAUSEA** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Becoming sick to his/her stomach when having medical treatments | 0 | 1 | 2 | 3 | 4 |
| 2. Some foods and smells make him/her sick to his/her stomach | 0 | 1 | 2 | 3 | 4 |
| 3. Becoming sick to his/her stomach when thinking of medical treatments | 0 | 1 | 2 | 3 | 4 |
| 4. Because feeling sick to his/her stomach, he/she does not want to be approached | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month,** how much of a **problem** has this been for **your child**…*

| **WORRY** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Getting scared when having to go to the hospital | 0 | 1 | 2 | 3 | 4 |
| 2. Getting scared about needle sticks (e.g. injections, blood tests, IVs) | 0 | 1 | 2 | 3 | 4 |

| **NUTRITION** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Food does not taste very good to him/her | 0 | 1 | 2 | 3 | 4 |
| 2. Being not hungry | 0 | 1 | 2 | 3 | 4 |
| 3. Having to drink a lot when chewing food | 0 | 1 | 2 | 3 | 4 |
| 4. Having constipation | 0 | 1 | 2 | 3 | 4 |
| 5. Having diarrhea | 0 | 1 | 2 | 3 | 4 |

| **THINKING** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty remembering things that he/she has heard | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty figuring out what to do when something bothers him/her | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty keeping his/her attention on things for a longer time | 0 | 1 | 2 | 3 | 4 |
| 4. Difficulty remembering things that he/she has read | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month,** how much of a **problem** has this been for **your child**…*

| **COMMUNICATION** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty asking the doctors or nurses questions | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty telling doctors or nurses how he/she feels | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty talking about his/her disease with other people | 0 | 1 | 2 | 3 | 4 |

| **OTHER COMPLAINTS** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Having pruritus | 0 | 1 | 2 | 3 | 4 |
| 2. Having painful skin infections | 0 | 1 | 2 | 3 | 4 |
| 3. Having a dry mouth | 0 | 1 | 2 | 3 | 4 |
| 4. Having dry or burning eyes | 0 | 1 | 2 | 3 | 4 |
| 5. Feeling lonely | 0 | 1 | 2 | 3 | 4 |
| 6. Difficulty breathing or being short of breath | 0 | 1 | 2 | 3 | 4 |

ID# _____

Date: _____

# PedsQL™

## Stem Cell Transplant Module

Version 1.0

**PARENT REPORT** for **YOUNG CHILDREN** (ages 5-7)



**DIRECTIONS**

Children who have had a transplant sometimes have special problems. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

**0** if it is **never** a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has this been for **your child**…*

| **PAIN AND HURT** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Pain in muscles and/or joints | 0 | 1 | 2 | 3 | 4 |
| 2. Pain | 0 | 1 | 2 | 3 | 4 |
| Pain in…<br><br>(please indicate where your child has pain) | | | | | |

| **FATIGUE AND SLEEP** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling tired | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling physically weak | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty sleeping through the night | 0 | 1 | 2 | 3 | 4 |
| 4. Having to sleep a lot | 0 | 1 | 2 | 3 | 4 |
| 5. Feeling too tired to do things that he/she likes to do | 0 | 1 | 2 | 3 | 4 |

| **NAUSEA** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Becoming sick to his/her stomach when having medical treatments | 0 | 1 | 2 | 3 | 4 |
| 2. Some foods and smells make him/her sick to his/her stomach | 0 | 1 | 2 | 3 | 4 |
| 3. Becoming sick to his/her stomach when thinking of medical treatments | 0 | 1 | 2 | 3 | 4 |
| 4. Because feeling sick to his/her stomach, he/she does not want to be approached | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month,** how much of a **problem** has this been for **your child**...*

| **WORRY** *(problems with...)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Worrying about side effects from medical treatment | 0 | 1 | 2 | 3 | 4 |
| 2. Worrying about whether or not medical treatments have been or are working | 0 | 1 | 2 | 3 | 4 |
| 3. Getting scared when having to go to the hospital | 0 | 1 | 2 | 3 | 4 |
| 4. Being scared of infections | 0 | 1 | 2 | 3 | 4 |
| 5. Worrying about whether he/she will grow properly | 0 | 1 | 2 | 3 | 4 |
| 6. Getting scared about needle sticks (e.g. injections, blood tests, IVs) | 0 | 1 | 2 | 3 | 4 |
| 7. Worrying that the disease will come back or relapse | 0 | 1 | 2 | 3 | 4 |
| 8. Worrying about whether he/she can return smoothly into normal life | 0 | 1 | 2 | 3 | 4 |
| 9. Not liking that his/her body looks different to that of healthy children or adolescents | 0 | 1 | 2 | 3 | 4 |
| 10. Worrying about whether other people do not want him/her because of the disease | 0 | 1 | 2 | 3 | 4 |

| **NUTRITION** *(problems with...)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Food does not taste very good to him/her | 0 | 1 | 2 | 3 | 4 |
| 2. Being not hungry | 0 | 1 | 2 | 3 | 4 |
| 3. Having to drink a lot when chewing food | 0 | 1 | 2 | 3 | 4 |
| 4. Having constipation | 0 | 1 | 2 | 3 | 4 |
| 5. Having diarrhea | 0 | 1 | 2 | 3 | 4 |

| **THINKING** *(problems with...)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty remembering things that he/she has heard | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty figuring out what to do when something bothers him/her | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty keeping his/her attention on things for a longer time | 0 | 1 | 2 | 3 | 4 |
| 4. Difficulty remembering things that he/she has read | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month,** how much of a **problem** has this been for **your child**…*

| **COMMUNICATION** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty asking the doctors or nurses questions | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty telling doctors or nurses how he/she feels | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty talking about his/her disease with other people | 0 | 1 | 2 | 3 | 4 |

| **OTHER COMPLAINTS** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Having pruritus | 0 | 1 | 2 | 3 | 4 |
| 2. Having painful skin infections | 0 | 1 | 2 | 3 | 4 |
| 3. Having a dry mouth | 0 | 1 | 2 | 3 | 4 |
| 4. Having dry or burning eyes | 0 | 1 | 2 | 3 | 4 |
| 5. Feeling lonely | 0 | 1 | 2 | 3 | 4 |
| 6. Difficulty breathing or being short of breath | 0 | 1 | 2 | 3 | 4 |

ID# _____

Date: _____

# PedsQL™

## Stem Cell Transplant Module

Version 1.0

**CHILD REPORT** (ages **8-12**)



**DIRECTIONS**

Children who have had a transplant sometimes have special problems. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

**0** if it is never a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has this been for you…*

| **PAIN AND HURT** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I ache or hurt in my muscles and/or joints | 0 | 1 | 2 | 3 | 4 |
| 2. I ache or hurt | 0 | 1 | 2 | 3 | 4 |
| I ache or hurt…<br><br>(please indicate where you ache or hurt) | | | | | |

| **FATIGUE AND SLEEP** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I feel tired | 0 | 1 | 2 | 3 | 4 |
| 2. I feel physically weak | 0 | 1 | 2 | 3 | 4 |
| 3. It is hard for me to sleep through the night | 0 | 1 | 2 | 3 | 4 |
| 4. I have to sleep a lot | 0 | 1 | 2 | 3 | 4 |
| 5. I feel too tired to do things that I like to do | 0 | 1 | 2 | 3 | 4 |

| **NAUSEA** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I become sick to my stomach when I have medical treatments | 0 | 1 | 2 | 3 | 4 |
| 2. Some foods and smells make me sick to my stomach | 0 | 1 | 2 | 3 | 4 |
| 3. I become sick to my stomach when I think of medical treatments | 0 | 1 | 2 | 3 | 4 |
| 4. Because I feel sick to my stomach, I do not want to be approached | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month**, how much of a **problem** has this been for you…*

| **WORRY** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I worry about side effects from medical treatment | 0 | 1 | 2 | 3 | 4 |
| 2. I worry about whether or not my medical treatments have been or are working | 0 | 1 | 2 | 3 | 4 |
| 3. I get scared when I have to go to the hospital | 0 | 1 | 2 | 3 | 4 |
| 4. I am scared of infections | 0 | 1 | 2 | 3 | 4 |
| 5. I worry about whether I will grow properly | 0 | 1 | 2 | 3 | 4 |
| 6. I get scared about needle sticks (e.g. injections, blood tests, IVs) | 0 | 1 | 2 | 3 | 4 |
| 7. I worry that my disease will come back or relapse | 0 | 1 | 2 | 3 | 4 |
| 8. I worry about whether I can return smoothly into normal life | 0 | 1 | 2 | 3 | 4 |
| 9. I do not like that my body looks different to that of healthy children or adolescents | 0 | 1 | 2 | 3 | 4 |
| 10. I worry about whether other people do not want me because of my disease | 0 | 1 | 2 | 3 | 4 |

| **NUTRITION** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Food does not taste very good to me | 0 | 1 | 2 | 3 | 4 |
| 2. I am not hungry | 0 | 1 | 2 | 3 | 4 |
| 3. I have to drink a lot when chewing food | 0 | 1 | 2 | 3 | 4 |
| 4. I have constipation | 0 | 1 | 2 | 3 | 4 |
| 5. I have diarrhea | 0 | 1 | 2 | 3 | 4 |

| **THINKING** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard for me to remember things that I have heard | 0 | 1 | 2 | 3 | 4 |
| 2. It is hard for me to figure out what to do when something bothers me | 0 | 1 | 2 | 3 | 4 |
| 3. It is hard for me to keep my attention on things for a longer time | 0 | 1 | 2 | 3 | 4 |
| 4. It is hard for me to remember things that I have read | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month,** how much of a **problem** has this been for you…*

| **COMMUNICATION** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard for me to ask the doctors or nurses questions | 0 | 1 | 2 | 3 | 4 |
| 2. It is hard for me to tell doctors or nurses how I feel | 0 | 1 | 2 | 3 | 4 |
| 3. It is hard for me to talk about my disease with other people | 0 | 1 | 2 | 3 | 4 |

| **OTHER COMPLAINTS** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I have pruritus | 0 | 1 | 2 | 3 | 4 |
| 2. I have painful skin infections | 0 | 1 | 2 | 3 | 4 |
| 3. I have a dry mouth | 0 | 1 | 2 | 3 | 4 |
| 4. I have dry or burning eyes | 0 | 1 | 2 | 3 | 4 |
| 5. I feel lonely | 0 | 1 | 2 | 3 | 4 |
| 6. It is hard for me to breathe or I am short of breath | 0 | 1 | 2 | 3 | 4 |

ID# _____

Date:_____

# PedsQL™

## Stem Cell Transplant Module

Version 1.0

**PARENT REPORT** for **TEENS** (ages **13-18**)



**DIRECTIONS**

Teens who have had a transplant sometimes have special problems. Please tell us **how much of a problem** each one has been for **your teen** during the **past ONE month** by circling:

0 if it is never a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has this been for **your child**…*

| **PAIN AND HURT** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Pain in muscles and/or joints | 0 | 1 | 2 | 3 | 4 |
| 2. Pain | 0 | 1 | 2 | 3 | 4 |
| Pain in…<br><br>(please indicate where your child has pain) | | | | | |

| **FATIGUE AND SLEEP** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling tired | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling physically weak | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty sleeping through the night | 0 | 1 | 2 | 3 | 4 |
| 4. Having to sleep a lot | 0 | 1 | 2 | 3 | 4 |
| 5. Feeling too tired to do things that he/she likes to do | 0 | 1 | 2 | 3 | 4 |

| **NAUSEA** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Becoming sick to his/her stomach when having medical treatments | 0 | 1 | 2 | 3 | 4 |
| 2. Some foods and smells make him/her sick to his/her stomach | 0 | 1 | 2 | 3 | 4 |
| 3. Becoming sick to his/her stomach when thinking of medical treatments | 0 | 1 | 2 | 3 | 4 |
| 4. Because feeling sick to his/her stomach, he/she does not want to be approached | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month,** how much of a **problem** has this been for **your child**…*

| **WORRY** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Worrying about side effects from medical treatment | 0 | 1 | 2 | 3 | 4 |
| 2. Worrying about whether or not medical treatments have been or are working | 0 | 1 | 2 | 3 | 4 |
| 3. Getting scared when having to go to the hospital | 0 | 1 | 2 | 3 | 4 |
| 4. Being scared of infections | 0 | 1 | 2 | 3 | 4 |
| 5. Worrying about whether he/she will grow properly | 0 | 1 | 2 | 3 | 4 |
| 6. Getting scared about needle sticks (e.g. injections, blood tests, IVs) | 0 | 1 | 2 | 3 | 4 |
| 7. Thinking about a later desire to have a child | 0 | 1 | 2 | 3 | 4 |
| 8. Worrying that the disease will come back or relapse | 0 | 1 | 2 | 3 | 4 |
| 9. Worrying about whether he/she can return smoothly into normal life | 0 | 1 | 2 | 3 | 4 |
| 10. Not liking that his/her body looks different to that of healthy children or adolescents | 0 | 1 | 2 | 3 | 4 |
| 11. Worrying about whether other people do not want him/her because of the disease | 0 | 1 | 2 | 3 | 4 |
| 12. Worrying about reaching puberty at the right time | 0 | 1 | 2 | 3 | 4 |

| **NUTRITION** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Food does not taste very good to him/her | 0 | 1 | 2 | 3 | 4 |
| 2. Being not hungry | 0 | 1 | 2 | 3 | 4 |
| 3. Having to drink a lot when chewing food | 0 | 1 | 2 | 3 | 4 |
| 4. Having constipation | 0 | 1 | 2 | 3 | 4 |
| 5. Having diarrhea | 0 | 1 | 2 | 3 | 4 |

| **THINKING** *(problems with…)* | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty remembering things that he/she has heard | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty figuring out what to do when something bothers him/her | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty keeping his/her attention on things for a longer time | 0 | 1 | 2 | 3 | 4 |
| 4. Difficulty remembering things that he/she has read | 0 | 1 | 2 | 3 | 4 |

*In the past **ONE month,** how much of a **problem** has this been for **your child…***

| **COMMUNICATION** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Difficulty asking the doctors or nurses questions | 0 | 1 | 2 | 3 | 4 |
| 2. Difficulty telling doctors or nurses how he/she feels | 0 | 1 | 2 | 3 | 4 |
| 3. Difficulty talking about his/her disease with other people | 0 | 1 | 2 | 3 | 4 |

| **OTHER COMPLAINTS** ***(problems with…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Having pruritus | 0 | 1 | 2 | 3 | 4 |
| 2. Having painful skin infections | 0 | 1 | 2 | 3 | 4 |
| 3. Having a dry mouth | 0 | 1 | 2 | 3 | 4 |
| 4. Having dry or burning eyes | 0 | 1 | 2 | 3 | 4 |
| 5. Feeling lonely | 0 | 1 | 2 | 3 | 4 |
| 6. Difficulty breathing or being short of breath | 0 | 1 | 2 | 3 | 4 |