

QUESTIONNAIRE CODE NUMBER: _____

RESPONDENT'S QUESTIONNAIRE

IN ANSWERING THE QUESTIONS BELOW, PLEASE CIRCLE A SINGLE NUMBER REPRESENTING YOUR BEST JUDGMENT, OR FILL-IN THE BLANKS WHERE APPROPRIATE.

We would like you to think back to the time when you first learned the nature of your child's illness. Below is a list of common feelings reported by parents when they first learn of their child's illness. For each feeling please circle the number that corresponds to how well it describes how you felt when you first learned the nature of your child's illness.

Feelings	Not at all Descriptive 1	Just Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
A. Guilty about your child's illness	1	2	3	4
B. Able to deal with whatever happened	1	2	3	4
C. That you might have done more to prevent or minimize your child's illness.	1	2	3	4
D. Overwhelmed at the responsibility of caring for your child.	1	2	3	4
E. Anxious	1	2	3	4
F. Unusually loving toward your child	1	2	3	4
G. Withdrawn	1	2	3	4
H. That you and your child could beat the illness.	1	2	3	4
I. Like rejecting the doctor's explanation.	1	2	3	4

Feeling	Not at all Descriptive 1	Just Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
J. Some relief at finally knowing what was wrong with your child.	1	2	3	4
K. Acceptance of your child's diagnosis.	1	2	3	4
L. Helpless.	1	2	3	4
M. Out of control	1	2	3	4
N. Angry	1	2	3	4
O. Shocked	1	2	3	4
P. Disbelieving	1	2	3	4
Q. Sad or tearful	1	2	3	4
R. Depressed	1	2	3	4

2. Did you have any other strong feelings when you first learned of your child's illness?

Yes: _____ No: _____

↓
If yes, what were these feelings? _____

3. Below is a list of the ways children often respond when they have a serious illness. For each of these, please circle the number that corresponds to how well the response describes the way your child acted when he or she first learned about his or her illness.

Response	Not at all Descriptive 1	Just Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
A. Angry	1	2	3	4
B. Despondent and sad	1	2	3	4
C. Withdrawn and detached	1	2	3	4
D. She/he did not seem any different than usual	1	2	3	4
E. Irritable	1	2	3	4
F. Anxious and fearful	1	2	3	4
G. She/he blamed me	1	2	3	4
H. She/he felt punished	1	2	3	4
I. She/he blamed others in the family	1	2	3	4

4. Below is a list of behaviors that children who are very ill often display. For each behavior, please circle the number that corresponds to how well it describes your child's behavior when she or he first became ill.

Behavior	Not at all Descriptive 1	Just Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
A. Sleep disturbances	1	2	3	4
B. Fears	1	2	3	4
C. Clinging	1	2	3	4

Behavior	Not at all Descriptive 1	Just Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
D. Afraid to be alone	1	2	3	4
E. Eating too much or too little	1	2	3	4
F. Jealous of siblings	1	2	3	4
G. Not wanting to be close to you	1	2	3	4
H. Unusually affectionate toward you	1	2	3	4
I. Problems with school	1	2	3	4
J. Talking about feelings more	1	2	3	4
K. Closer to siblings	1	2	3	4
L. Better at school	1	2	3	4
M. More aggressive with siblings and/or friends	1	2	3	4
N. Problems with siblings and/or friends	1	2	3	4
O. Becoming less involved in play activities	1	2	3	4
P. Becoming more involved in play activities	1	2	3	4
Q. Afraid to go to bed	1	2	3	4
R. Throwing tantrums	1	2	3	4

Behavior	Not at all Descriptive 1	Just Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
S. Unwilling to go to school	1	2	3	4
T. Complained alot about aches and pains that didn't have anything to do with his/her illness or treatment	1	2	3	4
U. Was unwilling to go to hospital	1	2	3	4
V. Was unwilling to take medication	1	2	3	4

5. Were there any other ways that your child responded when she/he was first diagnosed?

Yes: _____ No: _____

If yes, what ways were these? _____

WE WOULD LIKE YOU TO CONCENTRATE ON HOW YOU AND YOUR CHILD ARE DOING NOW. ALL OF THE FOLLOWING QUESTIONS REFER TO HOW THINGS ARE WITH YOU AND YOUR FAMILY RIGHT NOW. FIRST WE WOULD LIKE TO ASK YOUR OPINION ABOUT SOME VERY GENERAL ISSUES ABOUT YOURSELF AND YOUR FAMILY.

6. For each of the following pairs of statements, please indicate with a check mark which statement in each pair best describes your beliefs. Please check only one statement in each pair.

A-1 _____ I have often found that what is going to happen will happen.

OR

A-2 _____ Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

B-1 _____ What happens to me is my own doing.

OR

B-2 _____ Sometimes I feel that I don't have enough control over the direction my life is taking.

C-1 _____ When I make plans, I am almost certain that I can make them work.

OR

C-2 _____ It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.

D-1 _____ In my case, getting what I want has little or nothing to do with luck.

OR

D-2 _____ Many times we might just as well decide what to do by flipping a coin.

E-1 _____ Many times I feel that I have little influence over the things that happen to me.

OR

E-2 _____ It is impossible for me to believe that chance or luck play an important role in my life.

7. Listed below are statements about families. You are to decide which of these statements are true of your family and which are false. If you think the statement is TRUE or MOSTLY TRUE of your family, then circle the T (TRUE). If you think the statement is FALSE or MOSTLY FALSE of your family, then circle the F (FALSE).

Statement	TRUE	FALSE
1. Family members really help and support one another.	T	F
2. Family members often keep their feelings to themselves.	T	F
3. We fight a lot in our family.	T	F

Statement	TRUE	FALSE
4. We don't do things on our own very often in our family.	T	F
5. We feel it is important to be the best at whatever you do.	T	F
6. We often talk about political and social problems.	T	F
7. We spend most weekends and evenings at home.	T	F
8. Family members attend church, synagogue, or Sunday School fairly often.	T	F
9. Activities in our family are pretty carefully planned.	T	F
10. Family members are rarely ordered around.	T	F
11. We often seem to be killing time at home.	T	F
12. We say anything we want to around home.	T	F
13. Family members rarely become openly angry.	T	F
14. In our family, we are strongly encouraged to be independent.	T	F
15. Getting ahead in life is very important in our family.	T	F
16. We rarely go to lectures, plays or concerts.	T	F
17. Friends often come over for dinner or to visit.	T	F
18. We don't say prayers in our family.	T	F
19. We are generally very neat and orderly.	T	F
20. There are very few rules to follow in our family.	T	F

Statement	TRUE	FALSE
21. We put a lot of energy into what we do at home.	T	F
22. It's hard to "blow off steam" at home without upsetting somebody.	T	F
23. Family members sometimes get so angry they throw things.	T	F
24. We think things out for ourselves in our family.	T	F
25. How much money a person makes is not very important to us.	T	F
26. Learning about new and different things is very important in our family.	T	F
27. Nobody in our family is active in sports, Little League, bowling, etc.	T	F
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.	T	F
29. It's often hard to find things when you need them in our household.	T	F
30. There is one family member who makes most of the decisions.	T	F
31. There is a feeling of togetherness in our family.	T	F
32. We tell each other about our personal problems.	T	F
33. Family members hardly every lose their tempers.	T	F
34. We come and go as we want to in our family.	T	F
35. We believe in competition and "may the best man win."	T	F
36. We are not that interested in cultural activities.	T	F

Statement	TRUE	FALSE
37. We often go to movies, sports events, camping etc.	T	F
38. We don't believe in heaven or hell.	T	F
39. Being on time is very important in our family.	T	F
40. There are set ways of doing things at home.	T	F
41. We rarely volunteer when something has to be done at home.	T	F
42. If we feel like doing something on the spur of the moment we often just pick up and go.	T	F
43. Family members often criticize each other.	T	F
44. There is very little privacy in our family.	T	F
45. We always strive to do things just a little better the next time.	T	F
46. We rarely have intellectual discussions.	T	F
47. Everyone in our family has a hobby or two.	T	F
48. Family members have strict ideas about what is right and wrong.	T	F
49. People change their minds often in our family.	T	F
50. There is a strong emphasis on following rules in our family.	T	F
51. Family members really back each other up.	T	F
52. Someone usually gets upset if you complain in our family.	T	F
53. Family members sometimes hit each other.	T	F

Statement	TRUE	FALSE
54. Family members almost always rely on themselves when a problem comes up.	T	F
55. Family members rarely worry about job promotions, school grades, etc.	T	F
56. Someone in our family plays a musical instrument.	T	F
57. Family members are not very involved in recreational activities outside work or school.	T	F
58. We believe there are some things you just have to take on faith.	T	F
59. Family members make sure their rooms are neat.	T	F
60. Everyone has an equal say in family decisions.	T	F
61. There is very little groups spirit in our family.	T	F
62. Money and paying bills in openly talked about in our family.	T	F
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.	T	F
64. Family members strongly encourage each other to stand up for their rights.	T	F
65. In our family, we don't try that hard to succeed.	T	F
66. Family members often go to the library.	T	F
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).	T	F

8. A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

Statement	Not at all 1	Somewhat 2	Moderately So 3	Very Much So 4
A. I feel calm	1	2	3	4
B. I feel secure	1	2	3	4
C. I am tense	1	2	3	4
D. I am regretful	1	2	3	4
E. I feel at ease	1	2	3	4
F. I feel upset	1	2	3	4
G. I am presently worrying over possible misfortunes	1	2	3	4
H. I feel rested	1	2	3	4
I. I feel anxious	1	2	3	4
J. I feel comfortable	1	2	3	4
K. I feel self-confident	1	2	3	4
L. I feel nervous	1	2	3	4
M. I feel jittery	1	2	3	4
N. I feel "high strung"	1	2	3	4
O. I am relaxed	1	2	3	4

Statement	Not at all 1	Somewhat 2	Moderately So 3	Very Much So 4
P. I feel content	1	2	3	4
Q. I am worried	1	2	3	4
R. I feel over-excited and "rattled"	1	2	3	4
S. I feel joyful	1	2	3	4
T. I feel pleasant	1	2	3	4

1. A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you generally feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

Statement	Almost never 1	Sometimes 2	Often 3	Almost Always 4
A. I feel pleasant	1	2	3	4
B. I tire quickly	1	2	3	4
C. I feel like crying	1	2	3	4
D. I wish I could be as happy as others seem to be	1	2	3	4
E. I am losing out on things because I can't make up my mind soon enough	1	2	3	4
F. I feel rested	1	2	3	4

Statement	Almost never 1	Sometimes 2	Often 3	Almost Always 4
G. I am "calm, cool, and collected"	1	2	3	4
H. I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
I. I worry too much over something that really doesn't matter	1	2	3	4
J. I am happy	1	2	3	4
K. I am inclined to take things hard	1	2	3	4
L. I lack self-confidence	1	2	3	4
M. I try to avoid facing a crisis or difficulty	1	2	3	4
N. I feel blue	1	2	3	4
O. I am content	1	2	3	4
P. Some unimportant thought runs through my mind and bothers me	1	2	3	4
Q. I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
R. I am a steady person	1	2	3	4
S. I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

10. Below are groups of statements. Please read each group of statements carefully. Then pick out the one statement in each group which best describes the way you have been feeling the PAST WEEK, INCLUDING TODAY! Circle the number beside the statement you picked. If several statements in the group seem to apply equally well, circle each one. Be sure to read all the statements in each group before making your choice.

A. 0 - I do not feel sad.

1 - I feel sad.

2 - I am sad all the time and I can't snap out of it.

3 - I am so sad or unhappy that I can't stand it.

B. 0 - I am not particularly discouraged about the future.

1 - I feel discouraged about the future.

2 - I feel I have nothing to look forward to.

3 - I feel that the future is hopeless and that things cannot improve.

C. 0 - I do not feel like a failure.

1 - I feel I have failed more than the average person.

2 - As I look back on my life, all I can see is a lot of failures.

3 - I feel I am a complete failure as a person.

D. 0 - I get as much satisfaction out of things as I used to.

1 - I don't enjoy things the way I used to.

2 - I don't get real satisfaction out of anything anymore.

3 - I am dissatisfied or bored with everything.

E. 0 - I don't feel particularly guilty.

1 - I feel guilty a good part of the time.

2 - I feel quite guilty most of the time.

3 - I feel guilty all of the time.

F. 0 - I don't feel I am being punished.

1 - I feel I may be punished.

2 - I expect to be punished.

3 - I feel I am being punished.

G. 0 - I don't feel disappointed in myself.

1 - I am disappointed in myself.

2 - I am disgusted with myself.

3 - I hate myself.

- H. 0 - I don't feel I am any worse than anybody else.
1 - I am critical of myself for my weaknesses or mistakes.
2 - I blame myself all the time for my faults.
3 - I blame myself for everything bad that happens.
- I. 0 - I don't have any thought of killing myself.
1 - I have thoughts of killing myself, but I would not carry them out.
2 - I would like to kill myself.
3 - I would kill myself if I had the chance.
- J. 0 - I don't cry anymore than usual.
1 - I cry more now than I used to.
2 - I cry all the time now.
3 - I used to be able to cry, but now I can't cry even though I want to.
- K. 0 - I am no more irritated now than I ever was.
1 - I get annoyed or irritated more easily than I used to.
2 - I feel irritated all the time now.
3 - I don't get irritated at all by the things that used to irritate me.
- L. 0 - I have not lost interest in other people.
1 - I am less interested in other people than I used to be.
2 - I have lost most of my interest in other people.
3 - I have lost all of my interest in other people.
- M. 0 - I make decisions about as well as I ever could.
1 - I put off making decisions more than I used to.
2 - I have greater difficulty in making decisions than before.
3 - I can't make decisions at all anymore.
- N. 0 - I don't feel I look any worse than I used to.
1 - I am worried that I am looking old or unattractive.
2 - I feel that there are permanent changes in my appearance that make me look unattractive.
3 - I believe that I look ugly.

O. 0 - I can work about as well as before.

- 1 - It takes an extra effort to get started at doing something.
- 2 - I have to push myself very hard to do anything.
- 3 - I can't do any work at all.

P. 0 - I can sleep as well as usual.

- 1 - I don't sleep as well as I used to.
- 2 - I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
- 3 - I wake up several hours earlier than I used to and cannot get back to sleep.

Q. 0 - I don't get more tired than usual.

- 1 - I get tired more easily than I used to.
- 2 - I get tired from doing almost anything.
- 3 - I am too tired to do anything.

R. 0 - My appetite is no worse than usual.

- 1 - My appetite is not as good as it used to be.
- 2 - My appetite is much worse now.
- 3 - I have no appetite at all anymore.

S. 0 - I haven't lost much weight, if any, lately.

- 1 - I have lost more than 5 pounds.
- 2 - I have lost more than 10 pounds.
- 3 - I have lost more than 15 pounds.

I am purposely trying to lose weight
by eating less. Yes _____ No _____

T. 0 - I am no more worried about my health than usual.

- 1 - I am worried about physical problems such as aches and pains; or upset stomach;
or constipation.
- 2 - I am very worried about physical problems and it's hard to think of much else.
- 3 - I am so worried about my physical problems, that I cannot think about anything else.

U. 0 - I have not noticed any recent change in my interest in sex.

- 1 - I am less interested in sex than I used to be.
- 2 - I am much less interested in sex now.
- 3 - I have lost interest in sex completely.

11. For each of the following items, choose the one response which most accurately expresses your feelings. Circle the one number that indicates how well each statement describes you.

Statement	Not at All 0	Not Very 1	Slightly 2	Fairly 3	Very 4
A. When you have to talk in front of a class or group of people your own age, how afraid or worried to you usually feel?	0	1	2	3	4
B. When you are trying to win in a game or sport and you know that other people are watching you, how rattled or flustered do you usually get?	0	1	2	3	4
C. How much do you worry about whether other people will regard you as a success or failure in your job or career?	0	1	2	3	4
D. When in a group of people, do you have trouble thinking of the right things to talk about?	0	1	2	3	4
E. When you have made an embarrassing mistake or have done something that makes you look foolish, how long do you usually keep on worrying about it?	0	1	2	3	4
F. Do you find it hard to make talk when you meet new people?	0	1	2	3	4
G. How often do you worry about whether other people like to be with you?	0	1	2	3	4
H. How often are you troubled with shyness?	0	1	2	3	4

Statement	Not at all 0	Not Very 1	Slightly 2	Fairly 3	Very 4
I. When you are trying to convince other people who disagree with your ideas, how worried to you usually feel about the impression you are making?	0	1	2	3	4
J. When you think about the possibility that some of your friends or acquaintances might <u>not</u> have a good opinion of you, how concerned or worried do you feel about it?	0	1	2	3	4
K. How often do you feel worried or bothered about what other people think of you?	0	1	2	3	4
L. How much do you worry about how well you get along with other people?	0	1	2	3	4
M. How often do you feel self-conscious?	0	1	2	3	4
N. How often do you have the feeling that there is <u>nothing</u> you can do well?	0	1	2	3	4
O. In general, how unsure do you feel about your abilities?	0	1	2	3	4
P. Do you ever feel afraid or anxious when you are going into a room by yourself where other people have already gathered and are talking?	0	1	2	3	4

Statement	Practically Never 0	Once In a great while 1	Sometimes 2	Fairly Often 3	Very Often 4
Q. Do you ever think that you are a worthless individual?	0	1	2	3	4
R. How often do you worry about criticisms that might be made of your work by whoever is responsible for checking up on your work?	0	1	2	3	4
S. How often do you feel to blame for your mistakes?	0	1	2	3	4
T. How often do you feel that you dislike yourself?	0	1	2	3	4
U. How often do you feel inferior to most of the people you know?	0	1	2	3	4
V. Do you ever feel so discouraged with yourself that you wonder whether anything is worthwhile?	0	1	2	3	4
W. How often do you doubt that some day the people you know will look up to you and respect you?	0	1	2	3	4

NOW WE WOULD LIKE YOU TO THINK ABOUT YOUR HEALTH AND HOW YOU'VE BEEN FEELING LATELY.

12. For each of the statements below, please circle the number that best describes your feelings.

A. In general, how energetic have you felt lately?

1
Never have
any energy

2

3

4

5
Always full
of energy

B. In general, how has your health been lately?

1	2	3	4	5
My health has been poor				My health has been very good

C. In general, how have your spirits been lately?

1	2	3	4	5
My spirits have been very low				I've-been in very good spirits

13. For Questions A-E, please circle the number which best describes your health situation.

A. During the past three months on how many occasions were you ill or injured with different health problems?

none 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 or more

B. During the past three months on how many days did you have these health problems?

none 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 or more

C. During the past three months on how many days were these health problems severe enough to cause you to cancel any of your planned activities other than regular employment?

none 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 or more

D. During the past three months how many days of work, if any, did you miss as a result of these health problems?

none 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 or more

E. During the past three months how many times, if at all, did you visit a doctor or hospital for these health problems?

none 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 or more

14. Listed below are several health-related problems that people sometimes have. For each one, please circle the number that best describes how often you have had this problem in the last three months.

a. Your heart beating hard.

1	2	3
Never	Sometimes	Often

b. Shortness of breath when you were not exercising or working hard.

1	2	3
Never	Sometimes	Often

c. Nervousness, that is, being irritable, fidgety or tense.

1	2	3
Never	Sometimes	Often

d. Cold sweats.

1	2	3
Never	Sometimes	Often

e. Your hands trembling enough to bother you.

1	2	3
Never	Sometimes	Often

f. Headaches or pains in the head.

1	2	3
Never	Sometimes	Often

g. Fainting spells.

1	2	3
Never	Sometimes	Often

h. Feeling weak all over.

1	2	3
Never	Sometimes	Often

i. Periods of days, weeks, or months when you couldn't take care of things because you couldn't get going.

1	2	3
Never	So metimes	Often

j. Periods when you suddenly felt hot all over.

1	2	3
Never	Sometimes	Often

k. Periods of great restlessness that you could not sit long in a chair.

1	2	3
Never	Sometimes	Often

l. Acid or sour stomach happening several days in a week's time.

1	2	3
Never	Sometimes	Often

m. Your memory, that is not remembering things.

1	2	3
Never	Sometimes	Often

n. A fullness or clogging in your head or nose.

1	2	3
Never	Sometimes	Often

o. Personal worries that got you down physically, that is, made you physically ill.

1	2	3
Never	Sometimes	Often

Please go on to the next page.

15. For questions A and B, please circle the number which best describes your feelings about stress.

A. In general, how much do you believe that you can learn to control your reaction(s) to stress?

1	2	3	4	5
Believe Strongly		Somewhat Believe		Strongly Disbelieve

B. On the average, how stressed have you felt during the last week?

1	2	3	4	5
Not at all Stressed		Moderately Stressed		Extremely Stressed

THOSE ARE ALL THE QUESTIONS WE HAVE ON YOUR HEALTH. NOW WE WOULD LIKE TO ASK YOU SOME GENERAL THINGS ABOUT HOW YOU AND YOUR FAMILY ARE DEALING WITH YOUR CHILD'S ILLNESS.

16. We would like to know how your're dealing with you child's illness. Below is a list of things that mothers and fathers often do when trying to cope with their child's illness. For each thing, please circle the number that best describes how often you've done the behavior, and how effective the behavior has been in helping you deal with the pressures of your child's illness.

Behavior	Please indicate how often you've done the behavior on a scale from 1 to 5 where: 1=almost all of the time and 5=never.	Please indicate how helpful the behavior has been for you on a 1 to 5 scale where: 1=very helpful and 5=not at all helpful
1. Learning as much as you could about the different methods of treatment your child was receiving.	1 2 3 4 5	1 2 3 4 5
2. Setting concrete, short-term goals for your child.	1 2 3 4 5	1 2 3 4 5
3. Trying to avoid thinking about your child's illness.	1 2 3 4 5	1 2 3 4 5
4. Wishing that your child did not have this illness.	1 2 3 4 5	1 2 3 4 5

Behavior	How often 1=almost all of the time; 5 = never	How helpful 1=very helpful and 5=not at all helpful
5. Talking about your child's illness with family.	1 2 3 4 5	1 2 3 4 5
6. Talking about your child's illness with friends	1 2 3 4 5	1 2 3 4 5
7. Blaming yourself for your child's illness.	1 2 3 4 5	1 2 3 4 5
8. Drinking alcoholic beverages more than usual.	1 2 3 4 5	1 2 3 4 5
9. Smoking.	1 2 3 4 5	1 2 3 4 5
10. Eating more or less than usual.	1 2 3 4 5	1 2 3 4 5
11. Taking tranquilizers.	1 2 3 4 5	1 2 3 4 5
12. Practicing relaxation or meditation exercises.	1 2 3 4 5	1 2 3 4 5
13. Prayer, or in other ways asking for God's help and support.	1 2 3 4 5	1 2 3 4 5
14. Making plans, finding solutions to problems that come up.	1 2 3 4 5	1 2 3 4 5
15. Thinking about different possible outcomes for your child's illness.	1 2 3 4 5	1 2 3 4 5
16. Feeling acceptance about your child's illness.	1 2 3 4 5	1 2 3 4 5
17. Changing as a person in positive ways as a result of this experience	1 2 3 4 5	1 2 3 4 5

Behavior	How often 1=almost all of the time; 5=never	How helpful 1=very helpful and 5=not at all helpful
18. Feeling that in some ways your life has been enriched because of your child's illness.	1 2 3 4 5	1 2 3 4 5
19. Suffering from stomach aches or diarrhea.	1 2 3 4 5	1 2 3 4 5
20. Suffering from headaches.	1 2 3 4 5	1 2 3 4 5
21. Suffering from other physical symptoms.	1 2 3 4 5	1 2 3 4 5
22. Taking time to be by yourself.	1 2 3 4 5	1 2 3 4 5
23. Having more of a sense of humor about life.	1 2 3 4 5	1 2 3 4 5
24. Feeling that you are in control of what is happening to your child and your family.	1 2 3 4 5	1 2 3 4 5
25. Maintaining an attitude of hope.	1 2 3 4 5	1 2 3 4 5
26. Using mental imagery as a weapon against your child's cancer.	1 2 3 4 5	1 2 3 4 5
27. Changing your child's diet.	1 2 3 4 5	1 2 3 4 5
28. Changing your diet.	1 2 3 4 5	1 2 3 4 5
29. Changing your family's diet.	1 2 3 4 5	1 2 3 4 5
30. Doing more physical exercise.	1 2 3 4 5	1 2 3 4 5
31. Getting more rest.	1 2 3 4 5	1 2 3 4 5
32. Doing things that are fun for your child.	1 2 3 4 5	1 2 3 4 5

Behavior	How often 1=almost all of the time; 5=never	How helpful 1=very helpful and 5=not at all helpful
33. Doing things that are fun for yourself.	1 2 3 4 5	1 2 3 4 5
34. Doing things that are fun for your family.	1 2 3 4 5	1 2 3 4 5
35. Feeling that although you may not fully understand it, there is a purpose or meaning to your child's illness.	1 2 3 4 5	1 2 3 4 5
36. Feeling that through your own efforts you will personally be able to influence the outcome of your child's illness.	1 2 3 4 5	1 2 3 4 5
37. Feeling that the outcome of this illness is up to chance or fate.	1 2 3 4 5	1 2 3 4 5
38. Feeling that powerful people, such as the doctor, will be able to influence the outcome of your child's illness.	1 2 3 4 5	1 2 3 4 5
39. Accepting the facts of your child's illness as they have been presented to you, as well as the meaning of these facts.	1 2 3 4 5	1 2 3 4 5
40. Questioning the facts of your child's illness as they have been presented to you, as well as what these facts mean.	1 2 3 4 5	1 2 3 4 5
41. Trying to think positively about things.	1 2 3 4 5	1 2 3 4 5
42. Finding yourself thinking negatively about things.	1 2 3 4 5	1 2 3 4 5
43. Spending more time together as a family.	1 2 3 4 5	1 2 3 4 5

Behavior	How often 1=almost all of the time; 5=never	How helpful 1=very helpful and 5=not at all helpful
44. Spending time as a family laughing and joking together.	1 2 3 4 5	1 2 3 4 5

17. Are there any other ways you've attempted to deal with the stress of your child's illness?

Yes: _____ No: _____

↓
What ways are these? _____

18. Below is a list of feelings that parents have reported in response to a serious illness in their child. For each statement, please circle the number that corresponds to how well the statement describes your current feelings about your child's illness.

Feelings	Very Descriptive 1	Moderately Descriptive 2	A Little Descriptive 3	Not at all Descriptive 4
1. I sometimes feel guilty about my child's condition.	1	2	3	4
2. I usually feel able to deal with the problems arising from my child's illness.	1	2	3	4
3. I sometimes feel anxious.	1	2	3	4

Feelings	Very Descriptive 1	Moderately Descriptive 2	A Little Descriptive 3	Not at all Descriptive 4
4. I sometimes feel that I might have done more to prevent or minimize my child's illness.	1	2	3	4
5. I often feel overwhelmed by the responsibility of caring for my ill child.	1	2	3	4
6. I feel unusually loving toward my child.	1	2	3	4
7. I feel unusually indulgent toward my child.	1	2	3	4
8. I usually feel tired and fatigued because of the extra responsibilities resulting from my child's illness.	1	2	3	4
9. At times I feel like rejecting the doctor's explanations of my child's illness.	1	2	3	4
10. I feel that my own needs are sometimes neglected because of my child's illness.	1	2	3	4
11. I usually feel accepting of my child's condition.	1	2	3	4
12. I often feel helpless about my child's disease.	1	2	3	4
13. Sometimes I feel out of control about my child's illness.	1	2	3	4

19. Do you have any other feelings that are in response to your child's illness?

Yes: _____ No: _____

If yes, what feelings are these? _____

20. Below is a list of ways that children with serious illnesses often act or behave. For each one, please circle the number that corresponds with the description of your child's current responses or behaviors.

Behavior	Not at all Descriptive 1	Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
1. Angry about his/her illness.	1	2	3	4
2. Despondent and sad.	1	2	3	4
3. Withdrawn and detached.	1	2	3	4
4. No different from other children.	1	2	3	4
5. Irritable.	1	2	3	4
6. Anxious and fearful.	1	2	3	4
7. At times my child seems to enjoy being ill.	1	2	3	4
8. My child's reaction to medical treatment has generally been uncooperative.	1	2	3	4

Behavior	Not at all Descriptive 1	Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
9 . My child seems able to talk about his/her feelings more easily.	1	2	3	4
10 . She/he seems closer to his/her siblings.	1	2	3	4
11 . My child is more loving toward me.	1	2	3	4
12 . She/he seems emotionally distant from me.	1	2	3	4
13 . My child throws tantrums alot.	1	2	3	4
14 . My child is often unwilling to take his/her medication.	1	2	3	4
15 . She/he is often unwilling to go to school.	1	2	3	4
16 . My child complains alot about aches and pains that don't seem related to his/her illness.	1	2	3	4
17 . My child acts babyish for his/her age.	1	2	3	4
18 . My child is unusually mature for his/her age.	1	2	3	4
19 . She/he quarrels more with siblings and other children since his/her illness.	1	2	3	4
20 . She/he gets along better with siblings and other children since his/her illness.	1	2	3	4
21 . She/he has nightmares.	1	2	3	4

Behavior	Not at all Descriptive 1	Slightly - Descriptive 2	Moderately Descriptive 3	Very -- Descriptive 4
22. My child sometimes uses his/her symptoms to get special treatment at home.	1	2	3	4
23. My child sometimes seems to blame me for his/her condition.	1	2	3	4
24. At times my child seems to feel punished because of his/her illness.	1	2	3	4
25. She/he has alot of fears.	1	2	3	4
26. She/he clings alot.	1	2	3	4
27. My child is afraid to be alone.	1	2	3	4
28. She/he is afraid to go to bed.	1	2	3	4
29. She/he seems jealous of his/her siblings.	1	2	3	4

21. Are there any other ways your child behaves?

Yes: _____ No: _____

If yes, what ways are these? _____

NOW WE WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR EXPERIENCES WITH YOUR FRIENDS AND NEIGHBORS.

22. The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with friends. For each statement there are three possible answers: Yes, No, and Don't Know. Please circle the answer you choose for each item.

- | | | | |
|-----|----|------------|---|
| Yes | No | Don't Know | a. My friends give me the moral support I need. |
| Yes | No | Don't Know | b. Most other people are closer to their friends than I am. |
| Yes | No | Don't Know | c. My friends enjoy hearing about what I think. |
| Yes | No | Don't Know | d. Certain friends come to me when they have problems or need advice. |
| Yes | No | Don't Know | e. I rely on my friends for emotional support. |
| Yes | No | Don't Know | f. If I felt that one or more of my friends were upset with me, I'd just keep it to myself. |
| Yes | No | Don't Know | g. I feel that I'm on the fringe in my circle of friends. |
| Yes | No | Don't Know | h. There is a friend I could go to if I were just feeling down, without feeling funny about it later. |
| Yes | No | Don't Know | i. My friends and I are very open about what we think about things. |
| Yes | No | Don't Know | j. My friends are sensitive to my personal needs. |
| Yes | No | Don't Know | k. My friends come to me for emotional support. |
| Yes | No | Don't Know | l. My friends are good at helping me solve problems. |
| Yes | No | Don't Know | m. I have a deep sharing relationship with a number of my friends. |
| Yes | No | Don't Know | n. My friends get good ideas about how to do things or make things from me. |
| Yes | No | Don't Know | o. When I confide in friends, it makes me feel uncomfortable. |
| Yes | No | Don't Know | p. My friends seek me out for companionship. |
| Yes | No | Don't Know | q. I think that my friends feel that I'm good at helping them solve problems. |

Yes No Don't Know r. I don't have a relationship with a friend that is as intimate as other people's relationships with friends.

Yes No Don't Know s. I've recently gotten a good idea about how to do something from a friend.

Yes No Don't Know t. I wish my friends were much different.

23. How helpful or unhelpful have each of the following people been since you've been coping with the stresses of your child's illness? If you've had contact with several people in one category (for example, several neighbors) try to give us your overall impression.

a. Your neighbors:

Extremely helpful	1
Very helpful	2
Moderately helpful	3
Not very helpful	4
Extremely unhelpful	5
Does not apply	6

b. Your co-workers:

Extremely helpful	1
Very helpful	2
Moderately helpful	3
Not very helpful	4
Extremely unhelpful	5
Does not apply	6

c. Your friends:

Extremely helpful	1
Very helpful	2
Moderately helpful	3
Not very helpful	4
Extremely unhelpful	5
Does not apply	6

d. Other people who have children with a similar disease:

Extremely helpful	1
Very helpful	2
Moderately helpful	3
Not very helpful	4
Extremely unhelpful	5
Does not apply	6

24. On the questions below, please circle the number that best describes your feelings.

a. I am hesitant to tell friends the real nature of my child's illness.

Definitely true	1
Mostly true	2
Don't know	3
Mostly False	4
Definitely false	5
Does not apply	6

b. During the past month, there has been someone available when I wanted to talk.

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5
Does not apply	6

c. It is helpful to talk with other people who have children with an illness like my child's illness.

Definitely true	1
Mostly true	2
Don't know	3
Mostly false	4
Definitely false	5
Does not apply	6

d. People treat me differently when they find out about my child's illness.

Always	1
Very often	2
Sometimes	3
Almost never	4
Never	5

e. When people find out about my child's illness, some of them tend to avoid me.

Always	1
Very often	2
Sometimes	3
Almost never	4
Never	5

f. I tend to hide my child's illness from others.

Definitely true	1
Mostly true	2
Don't know	3
Mostly false	4
Definitely false	5

g. During the past month, I asked people around me for help:

All of the time	1
Most of the time	2
Some of the time	3
A little of the time	4
None of the time	5
Does not apply	6

25. During the past month, about how often did you get together with friends or relatives, like going out together or visiting in each other's homes?

Every day	1
Several days a week	2
About once a week	3
2 or 3 times in the month	4
About once	5

Please go on to the next page

26. We have asked you alot about various parts of your life. Now we would like to ask you about your life as a whole. How satisfied are you with your life as a whole these days? Circle the number that best described how satisfied you are with your life as a whole these days.

1	2	3	4	5
Completely Satisfied		Moderately Satisfied		Not at All Satisfied

THIS ENDS THE PART OF THE QUESTIONNAIRE ON YOUR FAMILY AND YOUR CHILD'S ILLNESS.

IT IS CUSTOMARY TO COMPILE A PROFILE OF A RESPONDING GROUP. SUCH INFORMATION CAN PROVE INVALUABLE TO RESEARCHERS, NOT ONLY WITH RESPECT TO THIS STUDY, BUT FUTURE STUDIES, AS WELL. AS WITH OTHER ANSWERS ON THIS QUESTIONNAIRE YOUR RESPONSES TO QUESTIONS IN THIS SECTION WILL REMAIN CONFIDENTIAL. PLEASE ANSWER EACH QUESTION AS ACCURATELY AS POSSIBLE BY CIRCLING THE NUMBER OF THE APPROPRIATE RESPONSE OR BY FILLING IN THE BLANK.

27. What is your Age? _____

28. What is your ethnic identity?

- ___ 1) American Indian
- ___ 2) White/Caucasian
- ___ 3) Asian
- ___ 4) Black
- ___ 5) Chicano/Mexican American/Latin
- ___ 6) Other (please specify): _____
- ___ 7) I do not identify with a particular ethnic group

29. Do you rent or own your current home?

Rent: _____ Own: _____

Approximately how long have you lived there: _____

30. What type of dwelling are you presently occupying?

- 1) Single Family House
- 2) Condominium
- 3) Apartment
- 4) Mobile Home
- 5) Other (Please Describe): _____

31. On the scale below, please put an X on the line that best described the highest level of formal education you have attained.

- 1) Less than high school (1-8 years)
- 2) Some high school (9-11 years)
- 3) High School graduate (12 years)
- 4) Vocational or training school after high school
- 5) Some college
- 6) College graduate
- 7) Some college or professional school after college graduation
- 8) Completed a Master's degree
- 9) Completed a Doctoral degree/ Law degree/ or, medical degree

32. Please give the best approximation of your net family income from all sources within your household (before taxes) in 1980.

- 1) Less than \$7,000
- 2) \$7,000 to \$9,999
- 3) \$10,000 to \$14,999
- 4) \$15,000 to \$19,999
- 5) \$20,000 to \$29,999
- 6) \$30,000 to \$39,999
- 7) \$40,000 to \$49,999
- 8) \$50,000 to \$59,999
- 9) \$60,000 and over

33. Thank you for your time. That completes the Questionnaire. We appreciate your assistance. Is there anything you would like to add to any of the topics we have discussed?

INTERVIEW CODE NUMBER: _____

General Information Sheet

(To be completed before interview)

A. Family's Name: _____

B. Date of Interview: _____

C. Interviewer's Name: _____

D. Time at which interview began: _____

Ended: _____

Total Time: _____ Hrs _____ Min.

E. Information on Patient:

(1) Name: _____

(2) Birthdate: _____

(3) Date of Diagnosis: _____

(4) Attending Physician: _____

(5) Diagnosis: _____

F. Person interviewed and his/her relationship to the patient:

G. Date of hospitalization: _____

H. Length of hospitalization: _____

I. Medical treatment during hospitalization: _____

J. Date of first remission: _____

HELLO. MY NAME IS _____. I AM FROM _____
AND I'M WORKING WITH THE STAFF OF CHILDREN'S HOSPITAL ON A STUDY.
BY TALKING WITH PARENTS LIKE YOURSELF, WE HOPE TO UNDERSTAND WHAT
FAMILIES LIKE YOUR OWN ARE GOING THROUGH, SO THAT WE CAN PROVIDE
BETTER SERVICES IN THE FUTURE. I FIRST NEED TO KNOW SOMETHING
ABOUT YOUR CHILD AND HIS/HER ILLNESS.

1. According to our records, your child's name is _____. Is that correct? (Interviewer: use the child's name or nickname throughout the interview wherever the letter "P" is included.)

2. What type of illness does _____ P _____ have? That is, could you describe, in your own words, _____ P _____ illness?

3. Approximately when, that is, in what month and year, was _____ P _____ diagnosed as having _____? (Interviewer: use the term provided by the parent in response to question 2.)

Month: _____ Year: _____

NOW I WOULD LIKE YOU TO TRY TO THINK BACK TO THE PERIOD
BEFORE _____ P _____ BECAME ILL AND WAS DIAGNOSED.

4. Before _____ P _____ illness, had you, or anyone close to you ever been afflicted by a life threatening illness or been in a life threatening accident?

Yes: _____ No: _____ (Skip to question 5)



a. What was this person's relationship to you? Was there anyone else? Who was that?	b. What was the illness or accident?	c. When did it happen?	d. What happened to _____?
1.			
2.			
3.			
4.			
5.			

e. Do you think that this (these) previous experiences helped you in any way to deal with _____ P's _____ illness?

Yes: _____ No: _____ (Skip to part 4-f)



In what ways? _____

f. Do you think that this (these) previous experience(s) made it more difficult for you to deal with _____ P's _____ illness?

Yes: _____ No: _____ (Skip to question 6)



In what ways? _____

5. Can you recall any other major crises that occurred in your family before P became ill? That is, can you think of any things or events that had a big effect on you and your family?

Yes: _____ No: _____ (Skip to question 6)



a. What was the event? Were there any others?	b. Approximately when did it happen?	c. Was this a positive or a negative event for you? (Interviewer: ask this <u>only</u> in ambiguous situations).
1.		
2.		
3.		
4.		
5.		

d. Do you think that this (these) previous event(s) helped you in any way to deal with P's illness?

Yes: _____ No: _____



In what ways? _____

e. Do you think that this (these) previous event(s) made it any more difficult for you to deal with _____ P's _____ illness?

Yes: _____ No: _____

In what ways? _____

6. What was your marital status right before _____ P _____ was diagnosed?

(1) never married

(4) separated

(2) married

(5) widowed

(3) divorced

(6) living in a marriage-like relationship

(7) other (describe): _____

a. How long had you been married at that time? _____

b. Was that your first marriage? Yes: _____ No: _____

7. Right before your child's illness, did you work outside of your home or go to school?

Yes: _____

No: _____ (Skip to question 8)

a. Which did you do? That is, did you have a job, or go to school, or both?

Job: _____

Both: _____

Student: _____

b(1). What did you do?

b(2). Where did you go to school?

c(1). On the average, how many
 hours per week did you work?

c(2). On the average, how many hours
 per week did you go to school?

d(1). How much did you like your
 job at that time? That is,
 would you say you liked it:

d(2). At that time, how much would you
 say that you liked school? That
 is, would you say you liked it:

- | | |
|--------------------|--------------------|
| (job) | (school) |
| (1) very much | (1) very much |
| (2) somewhat; or | (2) somewhat; or |
| (3) not very much? | (3) not very much? |

(Interviewer: if the R was married before diagnosis, ask question 8. If not, skip to question 9).

8. Did your husband (wife) work or go to school before _____ P _____ became ill?

Yes: _____ No: _____ (Skip to question 9)

a. Which did she/he do? That is, did he/she have a job, or go to school, or both?

Job: _____ Both: _____ Student: _____

b(1). What did he/she do?

b(2). Where did he/she go to school?

c(1). On the average, how many
hours per week did he/she work.

c(2). On the average, how many hours per
week did he/she go to school?

9. Before _____ P _____ became ill, had you had any experiences with hospitals?
That is, were you or anyone close to you ever hospitalized?

Yes: _____ No: _____ (Skip to question 10)

a. In general, before _____ P _____ illness, what had your experience with hospital staff and hospital personnel been like? That is would you say that in general your experiences had been mostly:

- (1) very positive
- (2) somewhat positive
- (3) somewhat negative; or
- (4) very negative?

b. What about your experiences made them mostly positive/negative?

NOW I WOULD LIKE YOU TO THINK ABOUT THE TIME WHEN _____ P
FIRST BECAME ILL OR WHEN YOU FIRST NOTICED THAT SOMETHING UNUSUAL
 WAS WRONG WITH HIM/HER.

10. What were the first signs of your child's illness?

a. What did you first think was wrong with him/her?

b. Where did you first take _____ P _____ ?

Family Physician: _____ Clinic: _____ CHLA/CHOC: _____ (Skip to part 10d)

c. What did your family physician (doctor at the clinic) tell you was wrong with _____ P _____?

d. How did you decide to take _____ P _____ to CHLA/CHOC?

e. Had you ever heard of CHLA/CHOC before?

Yes: _____ No: _____ (skip to part 10g)



f. What had you heard about it? _____

g. At that time, that is, when you first brought _____ P _____ to CHLA/CHOC, approximately how far did you live from the hospital?

_____ miles

and how long did it take you to get there?

_____ time

11. Who brought your child to the hospital that first time? (Interviewer: indicate everyone involved, including R, and their relationship to R).

12. Was your child hospitalized at that time?

Yes: _____

No: _____

Was he/she ever hospitalized at CHLA/CHOC?

Yes: _____ No: _____ (Skip to question 13)

a. How long was _____ P _____ hospitalized?

b. In general, how well were you treated by the hospital staff while your child was an in-patient? That is, were you treated:

1) Very well

2) Moderately well; or

3) Not very well

} → (skip to part 12-d)

c. In general, in what ways were you not treated well? _____

d. In general, how well do you think that _____ P _____ was treated by the hospital staff while he/she was an in-patient? That is, would you say he/she was treated:

1) Very well

2) Moderately well; or

3) Not very well

} → (Skip to part 12-f)

e. In general, in what ways was _____ P _____ not treated well? _____

f. Did you feel you were adequately informed about what was happening to P while he/she was hospitalized?

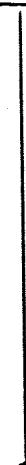
Yes: (Skip to part 12-g) No:



↓
What additional information would you have liked to have had at that time?

g. Did you feel you had enough freedom to be with P during all of his/her treatment and care while he/she was hospitalized?

Yes: (Skip to part 12-h) No:



↓
In what situations were you restricted or not permitted to be with your child?

h. Who visited P while he/she was in the hospital? Approximately how often did visit P ?

<u>Names</u>	<u>Relationship</u>	<u>How Often</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

NOW I WOULD LIKE YOU TO THINK ABOUT THE DAY YOU WERE TOLD THE NATURE OF YOUR CHILD'S ILLNESS. THAT IS, I WOULD LIKE YOU TO TRY TO THINK BACK TO (Interviewer: fill-in the month and year given to you by the R in response to Question 3.)

13. At the time of the initial diagnosis, who was told? That is, who was included at the initial conference? (Interviewer: list all people present, including R).

Person:

Relationship to R:

_____	_____
_____	_____
_____	_____
_____	_____

14. Who first told you about the nature of your child's illness?

15. Can you remember how P's illness was described to you at that time?

Yes: _____ No: _____ (Skip to part 15-b)

- a. Approximately what were the words used to describe the nature of P's illness?

b. How clear and easy to understand was the information you received in that first diagnostic conference? That is, was the information given:

(Interviewer: Show Card A)

- 1) very easy to understand;
- 2) easy to understand;
- 3) somewhat difficult to understand;
- 4) difficult to understand; or,
- 5) very difficult to understand?

c. In addition to being told about the illness, did you receive any written information at the time of the diagnosis?

Yes: _____ No: _____ (Skip to part 15-e)



d. How clear and easy to understand was the written information you received at that first diagnostic conference? That is, was the information: (Show Card A)

- 1) very easy to understand;
- 2) easy to understand;
- 3) somewhat difficult to understand;
- 4) difficult to understand; or,
- 5) very difficult to understand?

e. When you first learned the nature of your child's illness, was there anyone from the hospital staff, other than the physician, available to help you understand your child's diagnosis and treatment?

Yes: _____ No: _____ (Skip to Question 16)



f. Who was this person? Was there anyone else? Who was that?

g. Was this person actually in on the diagnostic conference?

Yes: _____

No: _____



About how soon after the conference did he/she become available to you? _____



h. How much did this person help you to understand your child's diagnosis and treatment. That is, was he/she:

- 1) very helpful;
- 2) somewhat helpful; or,
- 3) not very helpful?

16. Families choose many different ways to talk to their child about his/her illness.

a. Who first talked with P about the nature of his/her illness?

Someone other than the R: _____ (Go to part 16-b)
Who

The respondent: _____ (Skip to part 16-c)

P was never told: _____ (Skip to question 17)

b. Were you present when (other person) first told P about his/her illness?

Yes: _____

No: _____ (Skip to Question 17)



c. What did you/other person tell P about his/her illness that first time?

d. When was your child told about the nature of his/her illness? That is, about how long after you knew of his/her diagnosis, was he/she told? _____

e. Were there any aspects of the illness that were not discussed with your child at that time?

Yes: _____ No: _____ (Skip to question 17)



f. What were these? _____

g. Why were they not discussed with him/her? _____

17. At the time of P's diagnosis was there anyone from your immediate family (that is, anyone who was living in your home at that time) who was not present at the first diagnostic conference?

Yes: _____ No: _____ (Skip to question 18)



a. Did you tell all the other members of your immediate family who were not present at the original diagnostic conference about P's illness?

Yes: _____

No: _____

b. Who did you not tell? _____

c. Why? _____

d. Have you ever told him/her? _____

Yes: _____ No: _____

e. Who, in your immediate family did you tell of <u> P's </u> illness?	f. What did you tell this person was wrong with <u> P </u> .	g. How did he/she react? That is, what were his/her feelings?
1.		
2.		
3.		

18. Who, outside of your immediate family, did you tell about the nature of P's illness? That is, did you tell:

a. Any extended family members? That is, family members who do not live with you?

Yes: _____

No: _____ (Skip to part 18-b)



a-1. Who did you tell? (indicate relationship)	a-2. What did you tell him/her?	a-3. How soon, after you knew the diagnosis, did you tell this person?	a-4. How did he/she react?	a-5. Did you ever feel that he/she blamed you for <u>P</u> 's illness?
1.				
2.				
3.				
4.				
5.				

b. Did you tell any close friends or neighbors about the nature of P's illness?

Yes: _____ No: _____ (Skip to part 18-c)



b-1. Who did you tell?	b-2. What did you tell him/her?	b-3. How soon, after you knew the diagnosis did you tell this person	b-4. How did he/she react?	b-5. Did you ever feel that he/she blamed you for <u>P's</u> illness?
1.				

b-1. Who did you tell?	b-2. What did you tell him/her?	b-3. How soon, after you knew the diagnosis, did you tell this person?	b-4. How did he/she react?	b-5. Did you ever feel that he/she blamed you for <u>P's</u> illness?
2.				
3.				
4.				
5.				

c. Is P in day care or does s/he go to school?

Yes: _____ No: _____ (Skip to question 19)



d. Did you tell any school or day care officials about the nature of P's illness?

Yes: _____ No: _____ (Skip to question 19)



e. Which school officials did you talk to? _____

f. What did you tell them? _____

19. Very often parents have different theories or ideas about what caused their child's cancer. Do you have any thoughts or ideas about what caused P's cancer?

Yes: _____ No: _____ (Skip to question 20)

a. Could you please describe these? _____

20. I'm going to read to you a list of theories or factors that people come up with to explain the cause of childhood cancer. These are just people's beliefs about the causes of cancer. We don't really know if they are true or not. For each one, please tell me how important you feel it was in your own child's illness. That is, please tell me if you think it was: (Show Card B)

- 1) very important;
- 2) fairly important;
- 3) not very important; or,
- 4) not at all important.

- _____ 1. Your child's diet. That is, the things he/she ate before becoming ill.
- _____ 2. Stress or alot of tension in your home.
- _____ 3. God's will; fate.
- _____ 4. Your (your wife's) health while you (she) was pregnant with P .
- _____ 5. The environment. That is, things like smog or pollution in our environment.
- _____ 6. Something in your genes or your spouse's genes. That is, something your child inherited from you or your spouse.
- _____ 7. A virus.

_____ 8. Yours and your spouse's health habits. For example,
smoking or drinking.

_____ 9. The fact that you (your wife) nursed or didn't nurse _____ P _____.

_____ 10. Not giving your child enough love and affection.

AGAIN, I WANT TO EMPHASIZE THAT MOST OF THESE IDEAS ABOUT THE CAUSES OF CANCER ARE NOT TRUE-- OR WE JUST DON'T KNOW. NOW I WOULD LIKE YOU TO THINK ABOUT THE THINGS THAT HAVE HAPPENED SINCE _____ P _____ WAS DIAGNOSED.

21. About when did your child first go into remission? _____

22. Has he/she had any relapses since then? _____

Yes: _____ No: _____ (Skip to question 23)

 ↓
a. How many times? _____

23. Now I would like to ask you several questions about the outpatient clinic.

a. How often do you bring your child to the clinic? _____

b. On an average visit, how long do you stay at the clinic? _____

c-1. Who usually brings _____ P _____ to the clinic?

c-2. Does anyone else ever come with _____ (person in c-1) _____ ?

Yes: _____ No: _____ (Skip to part 23-d)



c-3. Who is that? _____

d. Do you have to make special arrangements on clinic days? That is, do you have to take off from work, hire a sitter for other children, etc?

Yes: _____ No: _____ (Skip to question 24)



e. What are the arrangements that you have to make? _____

f. Do you ever have problems making them?

Yes: _____ No: _____ (Skip to question 24)



g. What kinds of problems? _____

24. What is P's usual reaction on clinic days. That is, how does he/she behave:

a. Before coming to clinic? _____

b. While at clinic? _____

c. After clinic? That is, at home that evening? _____

d. In general, how well are you treated by the staff at the outpatient clinic?

That is, would you say that you're usually treated:

1) very well;

2) moderately well; or,

3) not very well?

} → (Skip to part 24 f)

→ e. In what ways are you not treated well? _____

f. In general, how well is P treated by the staff at the outpatient clinic?

That is, would you say she/he is usually treated:

1) very well;

2) moderately well; or,

3) not very well?

} → (Skip to question 25)

→ g. In what ways is P not treated well? _____

I WOULD LIKE TO NOW ASK YOU SOME QUESTIONS ABOUT THE STAFF AT CHLA/CHOC AND HOW THEY'VE WORKED WITH YOU AND YOUR FAMILY.

25. Did you ever receive a tour of the hospital or information on how to use the hospital or how to get around?

Yes: _____ No: _____ (Skip to question 26)



a. Approximately when was this? _____

b. How helpful to you was this? That is, would you say it was:

- 1) not very helpful;
- 2) somewhat helpful; or,
- 3) very helpful?

c. Are there ways it could have been more helpful to you?

Yes: _____ No: _____ (Skip to question 26)



d. In what ways? _____

26. Has anyone in your family including yourself, ever been helped by someone from the hospital to understand or deal with P's illness?

Yes: _____ No: _____ (Skip to question 27)



a. Who in your family including yourself, was helped? (indicate relationship)	b. Who helped him/her?	c. How?	d. How helpful was this for /her? That is, was it (1) very helpful; (2) somewhat helpful; or, (3) not very helpful?
1.			
2.			
3.			
4.			

27. Has P ever been helped by someone from the hospital to deal with the physical pain resulting from his/her treatment or illness?

Yes: _____ No: _____ (Skip to question 28)

a. Who helped P ? _____

b. How did (person in a) help P ? _____

c. How often has P been helped? That is, has he/she been helped:

- 1) very often;
- 2) sometimes; or,
- 3) not very often?

d. How helpful has (person in a) been in reducing P's pain?

That is, has he/she been:

- 1) very helpful;
- 2) somewhat helpful; or,
- 3) not very helpful?

(Interviewer: ask question 28 only if P is in school or day care.

Skip to question 29 if P is not in school or day care.)

28. Has anyone from the hospital ever helped you to get P back into school /day care?

Yes: _____ No: _____ (Skip to question 29)

a. Who helped you? _____

b. How did he/she help you? _____

c. How helpful was he/she? That is, was he/she:

- 1) very helpful;
- 2) somewhat helpful; or,
- 3) not very helpful?

NOW I WOULD LIKE YOU TO TELL ME SOME THINGS ABOUT
P's MEDICAL TREATMENT AT HOME.

29. What kind of medication does P take at home? How often?

Type

Frequency

IN MANY FAMILIES, WHEN SOMEONE IN THE FAMILY HAS A SERIOUS ILLNESS A NUMBER OF CHANGES TAKE PLACE IN THE FAMILY. I WOULD LIKE YOU TO THINK ABOUT SOME OF THE CHANGES THAT HAVE OCCURRED IN YOUR FAMILY SINCE _____ P _____ WAS DIAGNOSED.

33. Have you moved since _____ P _____ became ill?

Yes: _____ No: _____ (Skip to question 34)

a. When did you move? _____

b. Why did you move? _____

c. In general, has the move been a positive one for you and your family?

Yes: _____ No: _____

What has been negative about it? _____

d. How far, in miles, are you now from CHLA/CHOC? _____

e. How long does it take you to get to CHLA/CHOC? _____

34. Are you now working outside of your home or going to school?

Yes: _____ No: _____ (Skip to question 35)

a. Which do you do? That is, do you work outside your home, go to school, or both?



c-1. On the average, how many hours per week do you work?

c-2. On the average, how many hours per week do you go to school?

d-1. How much do you like your job? That is, would you say you like it:

d-2. How much do you like school? That is, would you say you like it:

- 1) very much;
- 2) somewhat; or,
- 3) not very much?

- 1) very much;
- 2) somewhat; or,
- 3) not very much?

35. What is your current marital status?

- (1) married
- (2) separated
- (3) divorced
- (4) widowed
- (5) living together
- (6) Other: _____

a. How long have you been married? _____

b. How satisfied are you with your current marital relationship? That is, would you say you are: (Show card C)

- 1) not at all satisfied;
- 2) a little satisfied;
- 3) moderately satisfied; or,
- 4) very satisfied?

c. Does your husband (wife) work or go to school?

Yes: _____ No: _____ (Skip to question 36)



d. Which does he/she do? That is, does he/she have a job, go to school, or both?

Job: _____ Both: _____ School: _____



e-1. What does he/she do?

e-2. Where does he/she go to school?

f-1. On the average, how many hours per week does he/she work?

f-2. On the average, how many hours per week does he/she go to school?

36. Can you think of any major changes in your family that have occurred since _____ P _____ was diagnosed?

Yes: _____ No: _____ (Skip to question 37)



a. What were these?	b. Did this help you deal with your child's illness?	c. If yes, in what ways?
1.		

a. What were these?	b. Did this help you deal with your child's illness?	c. If yes, in what ways?
2.		
3.		

VERY OFTEN WHEN SOMEONE IN A FAMILY HAS A SERIOUS ILLNESS, FAMILIES FIND THAT IT IS NECESSARY TO SEEK ASSISTANCE FROM A NUMBER OF PEOPLE AND ORGANIZATIONS. I WOULD NOW LIKE TO TALK WITH YOU ABOUT THE KINDS OF ASSISTANCE YOU'VE ASKED FOR AND RECEIVED.

37. A common problem families have when a family member is seriously ill is the increased expenses that they must meet.

a. In general, how much of a problem have the expenses from P's illness and treatment been for you? That is, have they been: (Show card D)

- 1) a very serious problem;
- 2) a serious problem;
- 3) a moderate problem;
- 4) a small problem; or,
- 5) no problem at all?

38. I'm going to read to you a list of financial resources sometimes used by families to meet the expenses of their children's illnesses and treatment. For each resource, I would like you to tell me if you ever requested financial support from it, if you received any money, and how helpful it was.

Resource	Requested Yes/No	Received Yes/No	How helpful. That is, was it: 1) very helpful 2) moderately helpful 3) only a little helpful
1. California Children Services (Or, CCS)			
2. Private Insurance			
3. Medi-Cal			
4. Leukemia Society			
5. American Cancer Society			

39. Are there other sources of money you've been able to take advantage of?

Yes: _____ No: _____ (Skip to question 40)

a. What are these sources? _____

40. When someone in a family has a serious illness, families often have to do without things or cutback on a lot of things that they would have been able to buy or do before the illness. Has this been true for your family?

That is, have you had to cutback on extras:

- 1) quite a bit;
- 2) a moderate amount;
- 3) a little; or,
- 4) not at all? (Skip to question 41)

a. What kinds of things have you cutback on? _____

b. How difficult have these cutbacks been for you and your family?

That is, have they been: (Show card E)

- 1) very difficult;
- 2) moderately difficult;
- 3) a little difficult; or,
- 4) not at all difficult?

41. There are some organizations and groups, outside of the hospital that can sometimes provide information and support to people who are in difficult situations.

a. Do you participate in any such clubs or organizations?

Yes: _____ No: _____ (Skip to part 41-c)

b. What organizations do you participate in?

↓

Organizations	Has your membership in this organization helped you in any way to deal with <u> P </u> illness?	If yes, in what ways has it been helpful?
1.		
2.		
3.		
4.		

c. Do you belong to any organized religion or religious group?

Yes: _____ No: _____ (Skip to part 41-g)



d. What religion is that? _____

e. How helpful has your religion been in helping you deal with P's illness?

That is, has it been:

- 1) very helpful;
- 2) somewhat helpful; or,
- 3) not at all helpful? (Skip to part 41-g)

f. In what ways has your religion been helpful to you? _____

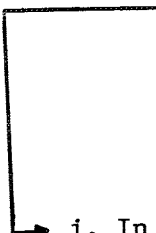
g. Have you had any counseling or therapy since P's illness was diagnosed?

Yes: _____ No: _____ (Skip to question 41-J)



h. How helpful has your counseling been in helping you deal with P's illness? That is, has it been:

- 1) very helpful;
- 2) somewhat helpful; or,
- 3) not at all helpful (Skip to part 41-j)



i. In what ways has your counseling been helpful to you? _____

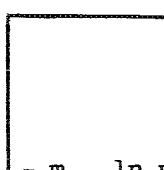
j. Has anyone else in your family, including P had any counseling or therapy since P's illness?

Yes: _____ No: _____ (Skip to question 42)

k. Who is that? _____

l. How helpful do you think the counseling has been for (go through for each person mentioned in k)? That is, has it been:

- 1) very helpful;
- 2) somewhat helpful; or,
- 3) not at all helpful (Skip to question 42)



m. In what ways has the counseling been helpful for (go through for each person mentioned in k)? _____

* 42. Do you have any neighbors which you consider as close friends?

Yes: _____ No: _____ (Skip to part 42-b)

↓
a. One or more than one?

1) one

2) More than one

b. In general, do you feel as if you have enough close friends?

Yes: _____ No: _____

c. In an emergency do you have relatives who would look after your family for a week?

Yes: _____ No: _____ Don't know: _____

d. In an emergency do you have friends who would look after your family for a week?

Yes: _____ No: _____ Don't know: _____

e. In an emergency do you have neighbors who would look after your family for a week?

Yes: _____ No: _____ Don't know: _____

f. If everything went badly, how many people could you turn to for real comfort and support? _____ (number of people)

g. Compared to the help that others can call on in a crisis, do you have:

- 1) much less
- 2) little less
- 3) little more
- 4) much more

43. Since finding out about P's illness, what kind of information were you provided with about your child's illness? That is, has it been mostly verbal, mostly written, or both?

written: _____ verbal: _____ both: _____

- a. I'm going to read a list of people to you who may have given you information on P's illness. For each one, please tell me whether this person provided you with information about the illness.

Person	Provided Information: Yes/No	If yes, was the information you received from (person) (1) very helpful; (2) somewhat helpful; or (3) not at all helpful.
1. <u>P's</u> Physician		
2. Nurses		
3. Social Worker		
4. Friends		
5. Relatives		
6. Psychologist/Therapist/ Counselor		

b. Has anyone else provided information to you?

Yes: _____ No: _____ (Skip to part 43-e)



c. Who was that? _____

d. Of all of the people who have given you information about P's illness, who has given you the most helpful information?

e. Have you sought out additional information about P's illness on your own?

Yes: _____ No: _____ (Skip to part 43-g)



f. From what source(s)? _____

g. Since finding out about P's illness, do you feel that you've received: (Show card F)

- 1) Much too little information about your child's illness;
- 2) a low amount of information about your child's illness;
- 3) the right amount of information about your child's illness;
- 4) a little too much information about your child's illness; or,
- 5) much too much information about your child's illness?

h. Can you think of any improvements that could be made in terms of the kind of information you received, or the way in which you received it?

Yes: _____ No: _____ (Skip to question 44)



i. What are they? _____

44. Since P became ill, have you, or anyone close to you, been affected by a severe illness or been in a serious accident?

Yes: _____ No: _____ (Skip to question 45)



a. What was this person's relationship to you? Was there anyone else? Who was that?	b. What was the illness or accident?	c. When did it happen?	d. What happened to _____?
1.			
2.			
3.			

45. Since P became ill, can you think of any major crises that have occurred in your family? That is, can you think of any things or events that had a big effect on you and your family?

Yes: _____ No: _____ (Skip to question 46)



a. What was the event? Were there any others?	b. Approximately when did it happen?	c. Was this a positive or a negative event for you? (Interviewer: ask this <u>only</u> in ambiguous situations)
1.		
2.		
3.		

FAMILIES REACT TO SERIOUS ILLNESSES IN MANY DIFFERENT WAYS. I WOULD LIKE YOU TO THINK ABOUT HOW THINGS ARE NOW IN YOUR FAMILY AND I WOULD LIKE TO ASK YOU SEVERAL QUESTIONS ABOUT HOW YOU AND YOUR FAMILY ARE DOING NOW.

46. From all the things you've done to help yourself deal with your child's illness, which has been:

a. Most helpful? _____

b. Which has been least helpful? _____

c. What has been your biggest problem resulting from your child's illness?

d. Have you managed to deal with this problem?

Yes: _____ No: _____



e-1. How have you dealt with it?

f. Have there been any major problems between you and P?

Yes: _____ No: _____ (Skip to question 47)



g. What are these? _____

h. How have you dealt with these problems? _____

47. Is there anything you could do for yourself that you are not presently doing to make the situation easier?

Yes: _____ No: _____ (Skip to question 48)



a. What are these things? _____

48. Is there anything that could be done for you that is not presently being done to make your situation easier?

Yes: _____ No: _____ (Skip to question 49)



a. What is that? _____

49. What advice would you give to a family in your situation to help them deal with the stresses and challenges of childhood cancer?

50. Do you have any children, other than P, who are living at home?

Yes: _____ No: _____ (Skip to question 58)



a. How many children do you have? _____

b. What are their names and birthdates?

Names:	Birthdates:	Age:	SEX:
1 _____	_____	_____	_____
2 _____	_____	_____	_____
3 _____	_____	_____	_____
4 _____	_____	_____	_____
5 _____	_____	_____	_____

(Interviewer: for questions 51-57, fill-in each child's name in the blanks and go through all of the questions for each child.)

51. To what extent do the following statements describe _____ and your relationship with one another? That is, would you say the statement describes your relationship with _____:

- 1) very well;
- 2) moderately well; or,
- 3) not very well?

- _____ 1. My relationship with _____ has become more superficial.
- _____ 2. I talk with _____ more about who does what in the family.
- _____ 3. My relationship with _____ is more demanding. That is, I expect more of him/her.
- _____ 4. My relationship with _____ has become more loving.
- _____ 5. I spend more time than usual with _____.
- _____ 6. The exchange of affectionate words and gestures between me and _____ has increased.
- _____ 7. The amount of quarreling and fighting with _____ has increased.
- _____ 8. _____ sometimes resents the amount of attention I give to P.
- _____ 9. _____ seems to feel somehow that he/she is responsible for P's illness.

52. To what extent have you observed the following changes in _____.

That is, have you noticed it occurring: (Show card G)

- 1) very often;
- 2) a moderate amount;
- 3) very rarely; or,
- 4) not at all?

- _____ 1. School problems.
- _____ 2. Tearfulness.
- _____ 3. Eating
- _____ 4. Fighting or arguing more.
- _____ 5. Complaining alot about physical ailments.
- _____ 6. Clinging more.
- _____ 7. More babyish than usual.
- _____ 8. More withdrawn than usual.
- _____ 9. More independent than usual.
- _____ 10. More helpful than usual.
- _____ 11. More loving than usual.
- _____ 12. More unhappy than usual.

53. Have you noticed any other changes in _____?

Yes: _____ No: _____ (Skip to question 54)



a. What changes are these? _____

54. Have there been any major problems between you and _____?

Yes: _____ No: _____ (Skip to question 55)



a. What are these problems? _____

b. How have you handled them? _____

55. Do you ever talk with _____ about _____ P's illness?

Yes: _____ No: _____ (Skip to question 56)



a. When you discuss _____ P's illness with _____, how much do you focus on each of the following areas? That is, do you focus on it: (Show card H)

- 1) a great deal;
- 2) a moderate amount;
- 3) very little; or,
- 4) not at all?

- _____ 1. Seeking support or reassurance from _____.
- _____ 2. Giving information to _____.
- _____ 3. Seeking advice from _____.
- _____ 4. Giving support and reassurance to _____.
- _____ 5. Expressing your feelings.
- _____ 6. Expressing your worries or concerns.
- _____ 7. Discussing _____ P's response to treatment.
- _____ 8. Discussing medical expenses.
- _____ 9. Asking _____ for help.
- _____ 10. Praying together for _____ P's recovery.
- _____ 11. Helping _____ to express his/her feelings.

56. Have you noticed any changes in _____'s relationship with his/her friends?

Yes: _____ No: _____ (Skip to question 57)



a. What are these changes? _____

b. Do you feel your children's friends visit your home more frequently, less frequently, or about the same as they did before P's illness?

Less: _____ Same: _____ More: _____

(Interviewer: Ask question 57 only if respondent has any children, including P in school. If respondent has no children in school than skip to question 58).

57. I am going to read you a list of statements that describe how children do in school. For each statement, please tell me how well it describes how _____ is doing in school. That is, does it describe _____: (Show card I)

- 1) very well;
- 2) moderately well;
- 3) not very well; or,
- 4) not at all?

_____ 1. _____ is doing very well academically in school. That is, he/she is getting A's and B's.

- _____ 2. _____ is doing about average academically in school. That is, he/she is getting mostly C's.
- _____ 3. _____ is having academic problems at school. That is, he/she is getting D's and F's.
- _____ 4. _____ has been having problems in the classroom.
- _____ 5. _____ is well-liked and accepted by his/her friends.
- _____ 6. _____ is isolated and teased by his/her classmates.
- _____ 7. _____'s teacher has expressed concern about his/her behavior in the last six months.
- _____ 8. _____'s teacher has expressed praise for him/her in the last six months.

(INTERVIEWER: Repeat the above question for each school-age child, including _____ P _____.)

(INTERVIEWER: Ask questions ~~58-62~~ only if respondent is married. If respondent is not married, skip to question ~~63~~).

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT YOU AND YOUR SPOUSE.

58. Please tell me how well the following statements describe you and your spouse's relationship since _____ P's _____ diagnosis. That is, please tell me if each statement describes your relationship: (Show card I)

- 1) very well;
- 2) moderately well;
- 3) a little; or,
- 4) not at all?

- _____ 1. Your time together has become more supportive. That is, you talk more about your feelings and express concern for each other.
- _____ 2. Your time together has become more businesslike. That is, you talk more about who will take care of which additional responsibility.
- _____ 3. There are more affectionate words and gestures exchanged between you and your spouse.
- _____ 4. There is more tension between you and your spouse.
- _____ 5. There is more quarreling and fighting between you and your spouse.
- _____ 6. You and your spouse spend less time talking to each other.
- _____ 7. At times your spouse appears to resent the amount of time you devote to caring for P .
- _____ 8. The frequency of sexual acitivity between you and your spouse has decreased.

59 . Sometimes a husband and wife have different reactions to the same health problems in their child. Overall, do you feel you and your spouse have basically the same or different attitudes toward your child's illness?

Same: _____ Different: _____

a. I am going to read you a list of things about your child's illness that you and your spouse might have felt differently about. For each one, please tell me if you think you and your spouse hold: (Show card J)

- 1) the same opinions or attitudes;
- 2) almost the same opinions or attitudes;
- 3) somewhat different opinions or attitudes; or,
- 4) very different opinions or attitudes.

- _____ 1. The causes of P's illness.
- _____ 2. How serious P's illness is.
- _____ 3. The meaning of P's illness for his/her present life.
- _____ 4. The meaning of P's illness for his/her future life.
- _____ 5. The extent to which P's activities should be restricted.
- _____ 6. The point at which you sought out a physician for P.
- _____ 7. The necessity of ongoing clinic visits.
- _____ 8. The need for home administered oral medication.
- _____ 9. The need to expose your child to other children with cancer.
- _____ 10. The importance of seeking out alternative treatment approaches for P. (For example, faith healing, megavitamins, laetril, etc)
- _____ 11. The importance of prayer and religion in curing your child.

a. Are there other ways in which you and your spouse have disagreed?

Yes: _____ No: _____ (Skip to question 60)



b. What ways are these? _____

60. Which parent would you say has been the primary decision-maker regarding treatment for P ?

Mother: _____ Father: _____ Both: _____

61. When you and your spouse talk about P's illness, how much of your communication focuses on the following things? That is, have you focused on these things:
(Show card H)

- 1) a great deal;
- 2) a moderate amount;
- 3) very little; or,
- 4) not at all?

_____ 1. Seeking support and reassurance from one another.

_____ 2. Giving information to one another.

_____ 3. Seeking advice about treatment from one another.

_____ 4. Discussing the child's response to treatment.

_____ 5. Discussing medical-related expenses.

_____ 6. Logistical problems (for example, transportation).

_____ 7. Expressing feelings to one another.

_____ 8. Praying together for your child.

_____ 9. Asking each other for help.

_____ 10. Blaming each other.

62. Have there been any major problems between you and your spouse?

Yes: _____ No: _____ (Skip to question 63)



a. What are these? _____

b. How have you handled these problems? _____

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT _____ P
AND HOW HE SHE IS DOING WITH HIS?HER ILLNESS.

63. Please describe your child's current condition: _____

64. What other health problems does your child have? _____

65. Do you believe that one day your child will be completely cured of this illness?

Yes: _____ Maybe: _____ No: _____ (Skip to question 66)
↓ ↓

a. If this happened, do you believe such a cure would result from: (Interviewer: these categories are not exclusive.)

- 1) medical treatment;
- 2) a miracle from God;
- 3) your own personal effort;
- 4) just chance or luck;
- 5) or, something else? (If yes) Describe: _____

b. Do you feel it will be possible for your child to live a completely normal life after this experience?

Yes: _____
 ↓

No: _____
 ↓

c. Why? _____

c-2. Why not? _____

66. How much pain or discomfort do you think P experiences on a daily basis?

That is, do you think he/she experiences: (Show card K)

- 1) a great deal of pain or discomfort;
- 2) a moderate amount of pain or discomfort;
- 3) a little pain or discomfort; or,
- 4) almost no pain or discomfort?

67. On a day to day basis, how much does P's illness and treatment keep her/him from performing normal activities? That is, does the illness keep her/him from his/her normal activities: (Show card H)

- 1) a great deal;
- 2) a moderate amount;
- 3) a little; or,
- 4) not at all?

68. In general, how much change in his/her appearance or energy level have you noticed in P s/he since began treatment for his/her illness? That is, have you noticed: (Show card L)

- 1) a great deal of physical change;
- 2) a moderate amount of physical change;
- 3) a little physical change; or,
- 4) almost no physical change?

69. I am going to read you a list of symptoms that children undergoing treatment sometimes have. For each symptom, please tell me if it is characteristic of your child now.

Symptom	Characteristic Yes/No
1. Loss of hair	
2. Weight gain	
3. Weight loss	
4. Fatigue	
5. Nausea	

a. Are there any other symptoms you've noticed:

Yes: _____ No: _____ (Skip to question 70)

↓

b. What are these? _____

70. About how many friends or playmates does your child have?

71. How well does P play with his/her friends? That is, would you say he/she plays:

- 1) very well with his/her friends;
- 2) moderately well with his/her friends; or,
- 3) not very well with his/her friends?

72. Does P have any chores or tasks to do around the house?

Yes: _____ No: _____ (Skip to question 73)



a. How well does P perform his/her chores in the house?

That is, does she/he perform them:

- 1) very well;
- 2) moderately well; or,
- 3) not very well?

73. How is P's mood in general? That is, would you say he/she is usually:

- 1) very happy;
- 2) moderately happy; or,
- 3) not very happy?

74. How do you think P generally feels about himself/herself? That is, do you think he/she generally feels:

- 1) very good;
- 2) moderately good; or,
- 3) not very good about him/herself?

75. How often do you think P is excluded or left out of things by his/her friends since the development of his/her illness? That is, do you think this happens:

- 1) almost all the time;
- 2) a moderate amount;
- 3) a little bit; or,
- 4) almost never?

76. How often do you think P is teased by his/her friends since the development of his/her illness? That is, do you think this happens:

- 1) almost all the time;
- 2) a moderate amount;
- 3) a little bit; or,
- 4) almost never?

77. Have you noticed any changes in P's play behavior?

Yes: _____ No: _____ (Skip to question 78)



a. What changes are these? _____

78. When talking about a serious illness with their child, parents tend to focus on different things. I'm going to read a list of things that parents can focus on. For each one, please tell me how much you focus on it when you talk with P about his/her illness. That is, please tell me if you: (Show card M)

- 1) never focus on it at all;
- 2) focus on it very little;
- 3) focus on it a moderate amount; or,
- 4) focus on it a great deal.

- _____ 1. Your child's feelings.
 _____ 2. Your feelings.
 _____ 3. Information about the illness.
 _____ 4. Instructions about self-care.

- _____ 5. Reassurance about the illness.
- _____ 6. Helping your child understand the meaning of his/her illness.
- _____ 7. Things about school.
- _____ 8. Trying to get P back into the activities he/she was involved
in before becoming ill.

a. Are there other things that you focus on with your child?

Yes: _____ No: _____ (Skip to question 79)



b. What are they? _____

(INTERVIEWER: Ask question 79 only if respondent has other children. If respondent does not have other children, skip to question 80.)

79. I am going to read you some statements about how you might act toward P
and your other child(ren). For each statement, please tell me if . it
describes your actions toward P and your other child(ren).

(Interviewer: Indicate yes or no on the line to the left of each statement)

- ___ 1. I spend more time with P than with my other children.
- ___ 2. I spend less time with P than with my other children.
- ___ 3. The exchange of affectionate words and gestures between P and me is greater than with my other children.
- ___ 4. I quarrel and fight with P more than with my other children.
- ___ 5. I treat P exactly the same as my other children.
- ___ 6. I do special nice things for P (for example, bring presents, make special foods) because of his/her illness, more often than I do for my other children.
- ___ 7. I am more lenient with P than with my other children.

NOW I WOULD LIKE TO ASK YOU SOME GENERAL QUESTIONS
ABOUT YOUR FAMILY AND P's ILLNESS.

80. A major illness is often considered a stressful event. However, the degree of stress caused by a particular illness varies considerably from family to family. In your estimation, to what extent has P's illness increased the amount of overall stress in your family? That is, would you say it has increased the stress:
- (Show card H)
- 1) a great deal;
 - 2) a moderate amount;
 - 3) very little;
 - 4) not at all?

81. Do you still find yourself talking about P's illness with other family members?

Yes: _____ No: _____

|
|

82. Sometimes family members' roles or tasks around the house change in response to sickness in one family member. For example, Mom may take time from work, or Dad may do more cooking. Did any such changes occur in your family?

Yes: _____ No: _____ (Skip to question 83)



a. What changes are these? _____

b. In general, how satisfied are you with these changes in roles or tasks?

That is, would you say you are: (Show card C)

- 1) very satisfied;
- 2) moderately satisfied;
- 3) somewhat dissatisfied; or,
- 4) very dissatisfied?

83. In general, how well do you think you and your family have handled P's illness so far. That is, would you say you've handled it: (Show card I)

- 1) very well;
- 2) moderately well;
- 3) not very well; or.
- 4) not at all

84. I am going to read you a list of common family activities that are often disrupted when a family member becomes ill. For each activity, please tell me how much it has been disrupted in your family. That is, tell me if it's been: (Show card N)

- 1) very disrupted;
- 2) moderately disrupted;
- 3) a little disrupted; or,
- 4) not at all disrupted.

- _____ 1. your spouses job.
- _____ 2. your job.
- _____ 3. family meals.
- _____ 4. family social activities.
- _____ 5. contact with family friends.
- _____ 6. your finances.
- _____ 7. your time with your husband/wife
- _____ 8. the time your family plays together, goes on outings, etc.
- _____ 9. the time you have to be by yourself.

85. I am going to read you some things related to P's illness that could produce stress for you. For each thing, please tell me if it has been:
(Show card 0)

- 1) very stressful for you;
- 2) moderately stressful for you;
- 3) a little stressful for you; or
- 4) not at all stressful for you.

- _____ 1. additional housekeeping chores.
- _____ 2. sleepless nights.
- _____ 3. additional expenses
- _____ 4. changes in your lifestyle.
- _____ 5. work interferred with.
- _____ 6. coordinating health care.
- _____ 7. concern about P's emotional health.
- _____ 8. concern about your other children.

- _____ 9. concern about your husband/wife.
- _____ 10. following P's medication schedule.
- _____ 11. going to the clinic.
- _____ 12. concern about P's future.

86. Thank you for your time. That completes the interview. We appreciate your assistance. Is there anything you would like to add to any of the topics we discussed today? _____

(INTERVIEWER: Complete questions 87-90 as soon as you've completed the interview, but not in the presence of the respondent.)

87. How open and cooperative was the R?

- | | | | | |
|--------------------|---|--------------------|---|--------------|
| 1 | 2 | 3 | 4 | 5 |
| Not at all
Open | | Moderately
Open | | Very
Open |

88. How nervous or anxious did the R appear to be?

1	2	3	4	5
Not at all Nervous		Moderately Nervous		Very Nervous

89. How difficult did it appear to be for the R to answer these questions?

1	2	3	4	5
Not at all Difficult		Moderately Difficult		Very Difficult

90. Please describe, briefly, anything unusual or of possible interest that occurred during the interview.

QUESTIONNAIRE CODE NUMBER: _____

*Johanna's
Copy*

HOSPITAL STAFF QUESTIONNAIRE

Child's Name: _____

Respondent's Name: _____

Respondent's Relationship to Child: _____

IN ANSWERING THE FOLLOWING QUESTIONS, PLEASE REFER TO THE CHILD AND RESPONDENT DESCRIBED ABOVE. FOR EACH QUESTION, PLEASE CIRCLE A SINGLE NUMBER REPRESENTING YOUR BEST JUDGMENT, OR FILL IN YOUR RESPONSE WHERE APPROPRIATE.

1. In what capacity have you known this child and respondent?

2. Approximately how long have you known:

A. This child?

less than 1 year 1-2 years 2-3 years greater than 3 years

B. This respondent?

less than 1 year 1-2 years 2-3 years greater than 3 years

3. As compared to other children with cancer, how well do you think this child is coping with his/her illness?

1	2	3	4	5	6
Not Coping Very Well		Coping Moderately Well		Coping Very Well	Don't Know

4. As compared to other families of children with cancer, how well do you think this respondent is coping with this child's illness?

1	2	3	4	5	6
Not Coping Very Well		Coping Moderately Well		Coping Very Well	Don't Know

5. In general, how well do you think this child has followed the medical regimen that was designated for him/her?

1	2	3	4	5	6
Not Very Well		Moderately Well		Very Well	Don't Know

6. As compared to other families, do you feel this family calls you or contacts you about this child:

1	2	3	4	5	6
Much more often than most families		About the same as most families		Much less than most families	Don't Know

7. Do you ever feel that someone from this family has contacted you about this child unnecessarily?

Yes: _____ No: _____

If yes, how often has this happened?

1	2	3	4	5	6
Very Often		A Moderate Amount		Very Rarely	Don't know

8. In your best judgment, to what extent has this child's illness interrupted normal family functioning?

1	2	3	4	5	6
Not at all		A Moderate Amount		A great Deal	Don't Know

9. As compared to other children with cancer, how much stress do you think this child is experiencing.

1 2 3 4 5 6
 Almost No A Moderate A great Don't Know
 Stress Amount Deal

10. As compared to other families of children with cancer, how much stress do you think the respondent is experiencing?

1 2 3 4 5 6
 Almost No A Moderate A great Don't Know
 Stress Amount Deal

11. In your opinion, what is this respondent's greatest strength in coping with this child's illness?

12. In your opinion, what is this respondent's greatest difficulty or problem in coping with this child's illness?

13. Below is a list of reactions of parents who have a child with cancer. For each one, please indicate how well you think it described the reactions of this respondent.

Reaction	Not at all Descriptive 1	Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4	Don't Know 5
1. Guilty about this child's illness.	1	2	3	4	5

13. Continued

Reaction	Not at all Descriptive 1	Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4	Don't Know 5
2. Anxious.	1	2	3	4	5
3. Overwhelmed at the responsibility of caring for this child.	1	2	3	4	5
4. Withdrawn.	1	2	3	4	5
5. Unwilling to accept the child's diagnosis.	1	2	3	4	5
6. Frequently helpless.	1	2	3	4	5
7. Frequently out of control.	1	2	3	4	5
8. Frequently angry.	1	2	3	4	5
9. Frequently depressed.	1	2	3	4	5
10. Accepting of the child's diagnosis.	1	2	3	4	5

14. Below is a list of ways that children respond when they have a serious illness. For each one, please indicate how well you think it described this child's response to his/her illness.

Response	Not at all Descriptive 1	Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4	Don't Know 5
1. Usually angry.	1	2	3	4	5
2. Usually despondent and sad.	1	2	3	4	5

14. Continued

Response	Not at all Descriptive 1	Slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4	Don't Know 5
3. Usually withdrawn and detached.	1	2	3	4	5
4. Usually happy.	1	2	3	4	5
5. Usually anxious and fearful.	1	2	3	4	5

15. Thank you for your time. That completes the questionnaire and we appreciate your assistance. Please use the space below if you would like to add anything to the issues presented within the questionnaire.

QUESTIONNAIRE CODE NUMBER: _____

*Johanna's
Copy*

SPOUSE'S QUESTIONNAIRE

IN ANSWERING THE QUESTIONS BELOW, PLEASE CIRCLE A SINGLE NUMBER REPRESENTING YOUR BEST JUDGMENT, OR FILL-IN THE BLANKS WHERE APPROPRIATE.

1. Very often parents have different theories or ideas about what caused their child's cancer. Do you have any thoughts or ideas about what caused your child's cancer?

Yes: _____ No: _____

↓
Could you please describe these? _____

2. Below is a list of theories or factors that people come up with to explain the cause of childhood cancer. These are just people's beliefs about the causes of cancer. We don't really know if they are true or not. For each one, please indicate how important you feel it was in your own child's illness. That is, circle the number that best describes how important you think it was for your child's cancer.

Theories	Very Important 1	Fairly Important 2	Not Very Important 3	Not at all Important 4
1. Your child's diet. That is, the things he/she ate before becoming ill.	1	2	3	4
2. Stress or alot of tension in your home.	1	2	3	4
3. God's will; fate.	1	2	3	4

Theories	Very Important 1	Fairly Important 2	Not Very Important 3	Not at all Important 4
4. Your (your wife's) health while you (she) was pregnant with your child.	1	2	3	4
5. The environment. That is, things like smog or pollution in our environment.	1	2	3	4
6. Something in your genes. That is, something your child inherited from you or your spouse.	1	2	3	4
7. A virus.	1	2	3	4
8. Yours and your spouse's health habits. For example, smoking or drinking.	1	2	3	4
9. The fact that you (your wife) nursed or didn't nurse your child.	1	2	3	4
10. Not giving your child enough love and affection.	1	2	3	4

3. Listed below are statements about families. You are to decide which of these statements are true of your family and which are false. If you think the statement is TRUE or MOSTLY TRUE of your family, then circle the T (TRUE). If you think the statement is FALSE or MOSTLY FALSE of your family, then circle the F (FALSE).

Statement	TRUE	FALSE
1. Family members really help and support one another.	T	F
2. Family members often keep their feelings to themselves.	T	F
3. We fight a lot in our family.	T	F

Statement	TRUE	FALSE
4. We don't do things on our own very often in our family.	T	F
5. We feel it is important to be the best at whatever you do.	T	F
6. We often talk about political and social problems.	T	F
7. We spend most weekends and evenings at home.	T	F
8. Family members attend church, synagogue, or Sunday School fairly often.	T	F
9. Activities in our family are pretty carefully planned.	T	F
10. Family members are rarely ordered around.	T	F
11. We often seem to be killing time at home.	T	F
12. We say anything we want to around home.	T	F
13. Family members rarely become openly angry.	T	F
14. In our family, we are strongly encouraged to be independent.	T	F
15. Getting ahead in life is very important in our family.	T	F
16. We rarely go to lectures, plays or concerts.	T	F
17. Friends often come over for dinner or to visit.	T	F
18. We don't say prayers in our family.	T	F
19. We are generally very neat and orderly.	T	F
20. There are very few rules to follow in our family.	T	F

Statement	TRUE	FALSE
21. We put a lot of energy into what we do at home.	T	F
22. It's hard to "blow off steam" at home without upsetting somebody.	T	F
23. Family members sometimes get so angry they throw things.	T	F
24. We think things out for ourselves in our family.	T	F
25. How much money a person makes is not very important to us.	T	F
26. Learning about new and different things is very important in our family.	T	F
27. Nobody in our family is active in sports, Little League, bowling, etc.	T	F
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.	T	F
29. It's often hard to find things when you need them in our household.	T	F
30. There is one family member who makes most of the decisions.	T	F
31. There is a feeling of togetherness in our family.	T	F
32. We tell each other about our personal problems.	T	F
33. Family members hardly every lose their tempers.	T	F
34. We come and go as we want to in our family.	T	F
35. We believe in competition and "may the best man win."	T	F
36. We are not that interested in cultural activities.	T	F

Statement	TRUE	FALSE
37. We often go to movies, sports events, camping etc.	T	F
38. We don't believe in heaven or hell.	T	F
39. Being on time is very important in our family.	T	F
40. There are set ways of doing things at home.	T	F
41. We rarely volunteer when something has to be done at home.	T	F
42. If we feel like doing something on the spur of the moment we often just pick up and go.	T	F
43. Family members often criticize each other.	T	F
44. There is very little privacy in our family.	T	F
45. We always strive to do things just a little better the next time.	T	F
46. We rarely have intellectual discussions.	T	F
47. Everyone in our family has a hobby or two.	T	F
48. Family members have strict ideas about what is right and wrong.	T	F
49. People change their minds often in our family.	T	F
50. There is a strong emphasis on following rules in our family.	T	F
51. Family members really back each other up.	T	F
52. Someone usually gets upset if you complain in our family.	T	F
53. Family members sometimes hit each other.	T	F

Statement	TRUE	FALSE
54. Family members almost always rely on themselves when a problem comes up.	T	F
55. Family members rarely worry about job promotions, school grades, etc.	T	F
56. Someone in our family plays a musical instrument.	T	F
57. Family members are not very involved in recreational activities outside work or school.	T	F
58. We believe there are some things you just have to take on faith.	T	F
59. Family members make sure their rooms are neat.	T	F
60. Everyone has an equal say in family decisions.	T	F
61. There is very little groups spirit in our family.	T	F
62. Money and paying bills in openly talked about in our family.	T	F
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.	T	F
64. Family members strongly encourage each other to stand up for their rights.	T	F
65. In our family, we don't try that hard to succeed.	T	F
66. Family members often go to the library.	T	F
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).	T	F

NOW WE WOULD LIKE TO ASK YOU SEVERAL QUESTIONS ABOUT HOW YOU AND YOUR FAMILY ARE DEALING WITH YOUR CHILD'S ILLNESS.

4. We would like to know how your're dealing with you child's illness. Below is a list of things that mothers and fathers often do when trying to cope with their child's illness. For each thing, please write in the number that best describes how often you've done the behavior, and how effective the behavior has been in helping you deal with the pressures of your child's illness.

Behavior	Please indicate how often you've done the behavior on a scale from 1 to 5; 1=almost all of the time and 5=never.	Please indicate how helpful the behavior has been for you on a 1 to 5 scale where: 1=very helpful and 5=not at all helpful
1. Learning as much as you could about the different methods of treatment your child was receiving.	1 2 3 4 5	1 2 3 4 5
2. Setting concrete, short-term goals for your child.	1 2 3 4 5	1 2 3 4 5
3. Trying to avoid thinking about your child's illness.	1 2 3 4 5	1 2 3 4 5
4. Wishing that your child did not have this illness.	1 2 3 4 5	1 2 3 4 5
5. Talking about your child's illness with family.	1 2 3 4 5	1 2 3 4 5
6. Talking about your child's illness with friends	1 2 3 4 5	1 2 3 4 5
7. Blaming yourself for your child's illness.	1 2 3 4 5	1 2 3 4 5
8. Drinking alcoholic beverages more than usual.	1 2 3 4 5	1 2 3 4 5
9. Smoking.	1 2 3 4 5	1 2 3 4 5
10. Eating more or less than usual.	1 2 3 4 5	1 2 3 4 5

Behavior	How often 1=almost all of the time; 5 = never	How helpful 1=very helpful and 5=not at all helpful
11. Taking tranquilizers.	1 2 3 4 5	1 2 3 4 5
12. Practicing relaxation or meditation exercises.	1 2 3 4 5	1 2 3 4 5
13. Prayer, or in other ways asking for God's help and support.	1 2 3 4 5	1 2 3 4 5
14. Making plans, finding solutions to problems that come up.	1 2 3 4 5	1 2 3 4 5
15. Thinking about different possible outcomes for your child's illness.	1 2 3 4 5	1 2 3 4 5
16. Feeling acceptance about your child's illness.	1 2 3 4 5	1 2 3 4 5
17. Changing as a person in positive ways as a result of this experience	1 2 3 4 5	1 2 3 4 5
18. Feeling that in some ways your life has been enriched because of your child's illness.	1 2 3 4 5	1 2 3 4 5
19. Suffering from stomach aches or diarrhea.	1 2 3 4 5	1 2 3 4 5
20. Suffering from headaches.	1 2 3 4 5	1 2 3 4 5
21. Suffering from other physical symptoms.	1 2 3 4 5	1 2 3 4 5
22. Taking time to be by yourself.	1 2 3 4 5	1 2 3 4 5
23. Having more of a sense of humor about life.	1 2 3 4 5	1 2 3 4 5

Behavior	How often 1=almost all of the time; 5=never	How helpful 1=very helpful and 5=not at all helpful
24. Feeling that you are in control of what is happening to your child and your family.	1 2 3 4 5	1 2 3 4 5
25. Maintaining an attitude of hope.	1 2 3 4 5	1 2 3 4 5
26. Using mental imagery as a weapon against your child's cancer.	1 2 3 4 5	1 2 3 4 5
27. Changing your child's diet.	1 2 3 4 5	1 2 3 4 5
28. Changing your diet.	1 2 3 4 5	1 2 3 4 5
29. Changing your family's diet.	1 2 3 4 5	1 2 3 4 5
30. Doing more physical exercise.	1 2 3 4 5	1 2 3 4 5
31. Getting more rest.	1 2 3 4 5	1 2 3 4 5
32. Doing things that are fun for your child.	1 2 3 4 5	1 2 3 4 5
33. Doing things that are fun for yourself.	1 2 3 4 5	1 2 3 4 5
34. Doing things that are fun for your family.	1 2 3 4 5	1 2 3 4 5
35. Feeling that although you may not fully understand it, there is a purpose or meaning to your child's illness.	1 2 3 4 5	1 2 3 4 5
36. Feeling that through your own efforts you will personally be able to influence the outcome of your child's illness.	1 2 3 4 5	1 2 3 4 5

Behavior	How often 1=almost all of the time; 5=never	How helpful 1=very helpful and 5=not at all helpful
37. Feeling that the outcome of this illness is up to chance or fate.	1 2 3 4 5	1 2 3 4 5
38. Feeling that powerful others, such as the doctor, will be able to influence the outcome of your child's illness.	1 2 3 4 5	1 2 3 4 5
39. Accepting the facts of your child's illness as they have been presented to you, as well as the meaning of these facts.	1 2 3 4 5	1 2 3 4 5
40. Questioning the facts of your child's illness as they have been presented to you, as well as what these facts mean.	1 2 3 4 5	1 2 3 4 5
41. Trying to think positively about things.	1 2 3 4 5	1 2 3 4 5
42. Finding yourself thinking negatively about things.	1 2 3 4 5	1 2 3 4 5
43. Spending more time together as a family.	1 2 3 4 5	1 2 3 4 5
44. Spending time as a family laughing and joking together.	1 2 3 4 5	1 2 3 4 5

5. Are there any other ways you've attempted to deal with the stress of your child's illness?

Yes: _____ No: _____

What ways are these? _____

6. Below is a list of feelings that parents have reported in response to a serious illness in their child. For each statement, please circle the number that corresponds to how well the statement describes your current feelings about your child's illness.

Feelings	Very Descriptive 1	Moderately Descriptive 2	A Little Descriptive 3	Not at all Descriptive 4
1. I sometimes feel guilty about my child's condition.	1	2	3	4
2. I usually feel able to deal with the problems arising from my child's illness.	1	2	3	4
3. I sometimes feel anxious.	1	2	3	4

Feelings	Very Descriptive 1	Moderately Descriptive 2	A Little Descriptive 3	Not at all Descriptive 4
4. I sometimes feel that I might have done more to prevent or minimize my child's illness.	1	2	3	4
5. I often feel overwhelmed by the responsibility of caring for my ill child.	1	2	3	4
6. I feel unusually loving toward my child.	1	2	3	4
7. I feel unusually indulgent toward my child.	1	2	3	4
8. I usually feel tired and fatigued because of the ex-ra responsibilities resulting from my child's illness.	1	2	3	4
9. At times I feel like rejecting the doctor's explanations of my child's illness.	1	2	3	4
10. I feel that my own needs are sometimes neglected because of my child's illness.	1	2	3	4
11. I usually feel accepting of my child's condition.	1	2	3	4
12. I often feel helpless about my child's disease.	1	2	3	4
13. Sometimes I feel out of control about my child's illness.	1	2	3	4

7. Do you have any other feelings that are in response to your child's illness?

Yes: _____ No: _____

If yes, what feelings are these? _____

8. Below is a list of ways that children with serious illnesses often act or behave. For each one, please circle the number that corresponds with the description of your child's current responses or behaviors.

Behavior	Very Descriptive 1	Moderately Descriptive 2	A Little Descriptive 3	Not at all Descriptive 4
1. My child seems able to talk about his/her feelings more easily.	1	2	3	4
2. She/he seems closer to his/her siblings.	1	2	3	4
3. My child is more loving toward me.	1	2	3	4
4. She/he seems emotionally distant from me.	1	2	3	4
5. My child throws tantrums alot.	1	2	3	4
6. My child is often unwilling to take his/her medication.	1	2	3	4
7. She/he is often unwilling to go to school.	1	2	3	4

Behavior	Very Descriptive 1	Moderately Descriptive 2	A Little Descriptive 3	Not at all Descriptive 4
8. My child sometimes uses his/her symptoms to get special treatment at home.	1	2	3	4
9. My child sometimes seems to blame me for his/her condition.	1	2	3	4
10. At times my child seems to feel punished because of his/her illness.	1	2	3	4
11. My child acts babyish for his/her age.	1	2	3	4
12. My child is unusually mature for his/her age.	1	2	3	4
13. She/he quarrels more with siblings and other children since his/her illness.	1	2	3	4
14. She/he gets along better with siblings and other children since his/her illness.	1	2	3	4
15. She/he has nightmares.	1	2	3	4
16. She/he has alot of fears.	1	2	3	4
17. She/he clings alot.	1	2	3	4
18. My child is afraid to be alone.	1	2	3	4
19. She/he is afraid to go to bed.	1	2	3	4
20. She/he seems jealous of his/her siblings.	1	2	3	4
21. My child complains alot about aches and pains that don't seem related to his/her illness.	1	2	3	4

9. Below is a list of statements describing the relationship between a husband and wife. For each statements, please circle the number that corresponds to how well each statement describes your relationship with your spouse since your child became ill.

Statements	Describes Your Relationship Very Well 1	Describes Your Relationship Moderately Well 2	Describes Your Relationship A Little 3	Does Not Describe Your Relationship At All 4
1. Our time together has become more supportive. That is, we talk more about our feelings and express concern for each other.	1	2	3	4
2. Our time together has become more businesslike. That is, we talk more about who will take care of which additional responsibility.	1	2	3	4
3. There are more affectionate words and gestures exchanged between me and my spouse.	1	2	3	4
4. There is more tension between me and my spouse.	1	2	3	4
5. There is more quarreling and fighting between me and my spouse.	1	2	3	4
6. My spouse and I spend less time talking to each other.	1	2	3	4
7. At times my spouse appears to resent the amount of time I devote to caring for our child.	1	2	3	4

Statements	Describes Your Relationship Very Well 1	Describes Your Relationship Moderately Well 2	Describes Your Relationship A Little 3	Does Not Describe Your Relationship At All 4
8. The frequency of sexual activity between me and my spouse has decreased.	1	2	3	4

10. Sometimes a husband and wife have different reactions to the same health problems in their child. Overall, do you feel you and your spouse have basically the same or different attitudes toward your child's illness?

Same: _____ Different: _____

11. Below is a list of things about your child's illness that you and your spouse might have felt differently about. For each one, please circle the number that corresponds to how you and your spouse's attitudes, about your child's illness, compare.

Attitudes	You have the same attitudes & opinions 1	You have almost the same attitudes & opinions 2	You have somewhat different attitudes & opinions 3	You have very different attitudes & opinions 4
1. The causes of your child's illness.	1	2	3	4
2. How serious your child's illness is.	1	2	3	4
3. The meaning of your child's illness for his/her present life.	1	2	3	4
4. The meaning of your child's illness for his/her future life.	1	2	3	4

Attitudes	You have the same attitudes & opinions 1	You have almost the same attitudes & opinions 2	You have somewhat different attitudes & opinions 3	You have very different attitudes & opinions 4
5. The extent to which your child's activities should be restricted.	1	2	3	4
6. The point at which you sought out a physician for your child.	1	2	3	4
7. The necessity of ongoing clinic visits.	1	2	3	4
8. The need for home administered oral medication.	1	2	3	4
9. The need to expose your child to other children with cancer.	1	2	3	4
10. The importance of seeking out alternative treatment approaches for your child. For example, faith healing, megavitamins, laetril, etc).	1	2	3	4
11. The importance of prayer and religion in curing your child.	1	2	3	4

12. Are there other ways in which you and your spouse have disagreed:

Yes: _____ No: _____
 ↓
 What ways are these? _____

13. When you and your spouse talk about your child's illness, how much of your communication focuses on the things listed below? For each statement listed below please circle the number that corresponds to how often the focus of your conversation with your spouse is as the statement describes.

Statement	You focus on this a great deal 1	You focus on this a moderate amount 2	You focus on this very little 3	You focus on this not at all 4
1. Seeking support and reassurance from one another.	1	2	3	4
2. Giving information to one another.	1	2	3	4
3. Seeking advice about treatment from one another.	1	2	3	4
4. Discussing the child's response to treatment.	1	2	3	4
5. Discussing medical-related expenses.	1	2	3	4
6. Logistical problems (for example, transportation).	1	2	3	4
7. Expressing feelings to one another.	1	2	3	4
8. Praying together for your child.	1	2	3	4
9. Asking each other for help.	1	2	3	4
10. Blaming each other.	1	2	3	4

14. Please circle the number below that best describes how satisfied you are with your current marital relationship?

1	2	3	4
Not at all Satisfied	A little Satisfied	Moderately Satisfied	Very Satisfied

15. Below is a list of statements describing the relationship between a parent and child. For each statement please circle the number that corresponds to how well the statement describes your relationship with your child since he/she became ill.

Statements	Describes Relationship Very Well 1	Describes Relationship Moderately Well 2	Describes Relationship A Little 3	Describes Relationship Not at all 4
1. I am more involved with my child.	1	2	3	4
2. There is more physical contact between me and my child.	1	2	3	4
3. We spend more time in conversation.	1	2	3	4
4. We do more special fun activities together.	1	2	3	4
5. We quarrel and fight more often.	1	2	3	4
6. We are more loving toward one another.	1	2	3	4
7. I am more detached from my child.	1	2	3	4

16. When talking about a serious illness with their child, parents tend to focus on different things. Below is a list of things that parents can focus on. For each one, please circle the number that corresponds to how much you focus on it when you talk with your child about his/her illness.

Statements	You focus on this a great deal 1	You focus on this a moderate amount 2	You focus on this very little 3	You focus on this not at all 4
1. Your child's feelings.	1	2	3	4

Statement	You focus on this a great deal 1	You focus on this a moderate amount 2	You focus on this very little 3	You focus on this not at all 4
2. Your feelings.	1	2	3	4
3. Information about the illness.	1	2	3	4
4. Instructions about self-care.	1	2	3	4
5. Reassurance about the illness.	1	2	3	4
6. Helping your child understand the meaning of his/her illness.	1	2	3	4
7. Things about school.	1	2	3	4
8. Trying to get your child back into the activities he/she was involved in before becoming ill.	1	2	3	4

17. Are there any other things you focus on when you discuss your child's illness with him/her?

Yes: _____ No: _____

↓
 What things are these? _____

18. Are there any other ways your child behaves?

Yes: _____ No: _____

If yes, what ways are these? _____

19. Please give the best approximation of your net family income from all sources within your household (before taxes) in 1980.

- _____ 1) Less than \$7,000
- _____ 2) \$7,000 to \$9,999
- _____ 3) \$10,000 to \$14,999
- _____ 4) \$15,000 to \$19,999
- _____ 5) \$20,000 to \$29,999
- _____ 6) \$30,000 to \$39,999
- _____ 7) \$40,000 to \$49,999
- _____ 8) \$50,000 to \$59,999
- _____ 9) \$60,000 and over

20. Thank you for your time. That completes the questionnaire. We appreciate your assistance. Is there anything you would like to add to any of the topics we have discussed?

