

RESPONDENT'S FIRST ILLNESS QUESTIONNAIRE

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

1. Below is a list of common feelings reported by parents of ill children. For each feeling please circle the number that corresponds to how well it describes how you felt when your child became sick.

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G. Withdrawn from 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

(continued next page)

1. cont'd

Feelings	Not at all Descriptive 1	Just slightly Descriptive 2	Moderately Descriptive 3	Very Descriptive 4
J. Some relief at learning 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. How helpful were each of the following people while your child was ill? you had contact with several people in one category (for example, several 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. 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

3. 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?

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INTERVIEW CODE NUMBER: \_\_\_\_\_

FIRST ILLNESS INTERVIEW

General Information Sheet

(To be completed before interview)

A. Family's Name: \_\_\_\_\_

B. Date of Interview: \_\_\_\_\_

C. Interviewer's Name: \_\_\_\_\_

D. Total Interview Time: \_\_\_\_\_ Hrs. \_\_\_\_\_ Min.

E. Information on Patient:

(1) Name: \_\_\_\_\_

(2) Birthdate: \_\_\_\_\_

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

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

G. Date of clinic visit: \_\_\_\_\_

H. Diagnosis: \_\_\_\_\_

I. Medical treatment prescribed: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

J. Date(s) of phone contacts: \_\_\_\_\_

HELLO. MY NAME IS \_\_\_\_\_. I AM FROM \_\_\_\_\_ AND I'M WORKING WITH THE STAFF OF THE EL TORO FAMILY PRACTICE CLINIC ON A STUDY. BY TALKING WITH PARENTS LIKE YOURSELF, WE HOPE TO UNDERSTAND WHAT THIS EXPERIENCE OF YOUR BABY'S FIRST ILLNESS HAS BEEN LIKE SO THAT WE CAN PROVIDE BETTER SERVICES IN THE FUTURE. I FIRST NEED TO KNOW SOMETHING ABOUT YOUR CHILD'S SPECIFIC ILLNESS EPISODE.

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. When P was ill, what type of illness did he/she have? That is, could you describe in your own words, P's illness?

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3. Approximately when, that is, what day and what month did P develop \_\_\_\_\_? (Interviewer: use the term provided by the parent in response to question 2.)

Day: \_\_\_\_\_ Month: \_\_\_\_\_

4. Approximately how long did this condition last?

\_\_\_\_\_ (number of days).

5. What were P's first symptoms? That is, what made you suspect that P might be ill?

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6. What did you first think was wrong with P?

\_\_\_\_\_

\_\_\_\_\_

7. What did you do when you noticed these first symptoms:

a) home remedy: (specify) \_\_\_\_\_

b) contact informal support system: (specify) \_\_\_\_\_

c) contact formal medical system: (specify) \_\_\_\_\_

d) other: (specify) \_\_\_\_\_

e) talk to spouse (specify): \_\_\_\_\_

f) nothing: \_\_\_\_\_

8. Do you remember having any particular feelings when you first noticed these symptoms?

Yes: \_\_\_\_\_ No

What were they? (specify) \_\_\_\_\_

9. Do you remember thinking or saying anything in particular to yourself when you first noticed these symptoms?

Yes: \_\_\_\_\_ No

What was this? \_\_\_\_\_

10. Who had primary responsibility for P during this illness?

a) respondent

b) respondent and spouse

c) spouse

d) relative

e) other (specify): \_\_\_\_\_

11. What made you decide to contact the family practice clinic?

a) worsening of symptoms (specify): \_\_\_\_\_

b) persistence of symptoms (specify): \_\_\_\_\_

11. c) own anxiety (specify): \_\_\_\_\_

d) advice from friend, neighbor, relative: \_\_\_\_\_

e) urging of spouse: \_\_\_\_\_

f) other: \_\_\_\_\_

12. What did the doctor say was wrong with P?

a) cold      b) ear ache      c) stomach problem      d) other (specify): \_\_\_\_\_

e) nothing      f) don't remember      \_\_\_\_\_

13. How clear and easy to understand was the doctor's explanation of P's illness?

1	2	3	4	5
very easy to understand	easy to understand	somewhat difficult to understand	difficult to understand	very difficult to understand

14. Did the doctor prescribe any medication for P?

Yes: \_\_\_\_\_ No

a) If so, do you remember what it was? \_\_\_\_\_

b) How often was P supposed to take this medicine? \_\_\_\_\_

1) once a day

2) 3x a day

3) 4x a day

4) other

5) don't remember

c) Did the doctor tell you to give P any other medicine?

Yes: \_\_\_\_\_ No

If so, what? \_\_\_\_\_

15. Did you have any problems in getting P to take the medication?

Yes: \_\_\_\_\_ No

How did you handle this? \_\_\_\_\_

\_\_\_\_\_

16. What else did the doctor tell you to do for P?

- |                           |                                 |
|---------------------------|---------------------------------|
| a) increase fluid intake  | b) avoid certain foods          |
| c) keep inside            | d) give bath if fever increases |
| e) use vaporizer or steam | f) nothing                      |
| g) other (specify): _____ | h) don't remember               |
- 

17. How clear and easy to understand were the doctor's instructions for P's care?

- |                            |                       |   |                            |                                 |
|----------------------------|-----------------------|---|----------------------------|---------------------------------|
| 1                          | 2                     | 3   | 4                          | 5                               |
| very easy<br>to understand | easy<br>to understand | somewhat<br>difficult<br>to<br>understand | difficult<br>to understand | very difficult<br>to understand |

18. How medically competent did the doctor seem to be in terms of treating your baby's illness?

- |            |   |   |   |           |
|------------|---|---|---|-----------|
| 1          | 2 | 3 | 4 | 5         |
| Not at all |   |   |   | Extremely |

19. How understanding of you as a person did you feel the doctor to be?

- |            |   |   |   |                         |
|------------|---|---|---|-------------------------|
| 1          | 2 | 3 | 4 | 5                       |
| Not at all |   |   |   | Extremely understanding |

a. What did he/she do or didn't do to make you feel this way? \_\_\_\_\_

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20. Did you feel better, worse, or the same after you had taken P to the clinic?

- |                   |                         |      |
|-------------------|-------------------------|------|
| Better:           | Worse:                  | Same |
| In what way?      | In what way?            |      |
| a) less anxious   | a) more anxious         |      |
| b) more competent | b) confused, frightened |      |
| c) reassured      | c) other: _____         |      |
- ( see next page )



20. cont'd

Better:

In what way?

d) had specific things to do for P.

e) felt like good mother

f) other \_\_\_\_\_

21. How important do you think the clinic visit was in helping  P  to recover?

1	2	3	4	5
Not at all important	slightly important	fairly important	quite important	extremely important

22. Did you give your baby any other kinds of non-prescription medicines in addition to what the doctor recommended:

Yes: \_\_\_\_\_ No

a) If yes, what were these? \_\_\_\_\_

b) What made you decide to use this medication?

1) child's symptom

2) advice of friend, neighbor

3) advice from spouse

4) previous positive experience with medication

5) disagreement with doctor

6) having heard this was useful

7) other (specify): \_\_\_\_\_

8) DK

23. Was there any other way in which you treated your baby after you went to the clinic?

Yes: \_\_\_\_\_ No

a) What else did you do? \_\_\_\_\_



25) a. I'm going to read a list of people to you who may have given you information about 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. Friends, Neighbors		
4. Relatives		
5. Spouse		
6. Mother, Mother-in-law		

b. Did anyone else give you information?

Yes:

No

Who was that? \_\_\_\_\_

c. Of all of the people who gave you information about P's illness, who gave you the most helpful information?

\_\_\_\_\_

26) What do you think caused P's illness?

- a) exposure to other sick person
- b) exposure to draft or cold
- c) unexplained exposure to virus, "germ"
- d) exposure in public place
- e) chance
- f) stress or tension in the family
- g) mother's health while she was pregnant
- h) environmental pollutants
- i) not nursing baby
- j) DK
- k) other: \_\_\_\_\_

27) Do you think there was anything you might have done to prevent P becoming ill?

Yes: \_\_\_\_\_ No

If so, what? (specify): \_\_\_\_\_

28) Did you have any lasting thoughts or feelings about the experience of P becoming sick:

Yes: \_\_\_\_\_ No

- a) anxiety
- b) depression
- c) anger
- d) relief
- e) other (specify): \_\_\_\_\_

29) Did this experience cause you to change your caretaking of P in any way?

Yes: \_\_\_\_\_ No

a) pay more attention to early symptoms

b) don't expose to cold

c) don't expose to public places

d) don't expose to sick people

e) other (specify): \_\_\_\_\_

30) Has there been any aftermath for P of this illness? That is, have you noticed any lasting effects on P's general health or behavior that you attribute to this illness?

Yes: \_\_\_\_\_ No

If so, what? \_\_\_\_\_

\_\_\_\_\_

31) Has P been sick at all since this illness? Yes: \_\_\_\_\_ No

a. How many times? \_\_\_\_\_

b. What was this illness(es)? \_\_\_\_\_

How was it handled? \_\_\_\_\_

\_\_\_\_\_

32) Do you think this illness first illness affected P in any other way?

a. eating problems

b. more irritable

c. more cheerful

d. sleeping problems

e. more fearful

f. no change

g. other (specify): \_\_\_\_\_

33) Do you think P is more vulnerable now to catching colds or other infections?

1

2

3

4

5

Not at all

Very much

34) Do you think P's illness affected your relationship with P in any way?

Yes:

No

a. In what way(s) \_\_\_\_\_  
\_\_\_\_\_

35) What did you tell your spouse about P's illness?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

36) Were there any aspects of P's illness that you did not discuss with your spouse?

Yes:

No

a. What were these? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

b. Why didn't you discuss these? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

37) What was your spouse's reaction to P's illness?

a) slight worry/concern

b) ignoring/non-involvement

c) significant anxiety

d) other (specify): \_\_\_\_\_

e) NA

f) DR

38) When you and your spouse talked about P's illness, how much of your communication focused on the following things? That is, have you focused on these things:

- 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 about the child.
- 3. Seeking advice about treatment from one another.
- 4. Discussing the child's response to treatment.
- 5. Discussing medically-related expenses.
- 6. Logistical problems (for example, babysitting, transportation).
- 7. Expressing positive feelings to one another.
- 8. Expressing negative feelings to one another.
- 9. Praying together for your child.
- 10. Asking each other for help.
- 11. Blaming each other for P's illness.

39) Please tell me how well the following statements describe how you and your spouse behaved during P's illness. That is, please tell me if each statement describes how you behaved:

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

(see next page)

39. cont'd

- \_\_\_\_\_ 1. You and your spouse were more supportive of each other than usual. That is, you talked more about your feelings and expressed concern for each other.
- \_\_\_\_\_ 2. You and your husband talked more than usual about who would take care of which responsibilities related to P's care.
- \_\_\_\_\_ 3. There were more affectionate words and gestures than usual between you and your spouse.
- \_\_\_\_\_ 4. There was more tension than usual between you and your spouse.
- \_\_\_\_\_ 5. There was more quarreling and fighting than usual between you and your spouse.
- \_\_\_\_\_ 6. You and your spouse spent less time than usual talking to each other.
- \_\_\_\_\_ 7. At times your spouse appeared to resent the amount of time you took to care for  P .
- \_\_\_\_\_ 8. The frequency of sexual activity between you and your spouse decreased.

40. Sometimes a husband and wife have different reactions to the same health problem in their child. Overall, do you feel you and your spouse had 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:

(see next page)



40. cont'd

- 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 was.
- \_\_\_\_\_ 3. The point at which you sought out a physician for  P  .
- \_\_\_\_\_ 4. The need for home administered medications.
- \_\_\_\_\_ 5. The importance of seeking out alternative treatment approaches for  P  . (For example, from neighbors, relatives, etc.)
- \_\_\_\_\_ 6. The importance of prayer for your child.

b) Are there other ways in which you and your spouse disagreed about P's illness?

Yes: No

What ways were these? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

41. Do you think P's illness affected your relationship with your husband in any way?

Yes: No

In what way? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

FAMILIES REACT TO A FIRST ILLNESS 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.

42. From all the things you did to deal with your child's illness, which was:

a. Most helpful? \_\_\_\_\_

\_\_\_\_\_

b. Which was least helpful? \_\_\_\_\_

\_\_\_\_\_

c. What was the biggest stress for you during P's illness?

\_\_\_\_\_

\_\_\_\_\_

d. How did you deal with this?

\_\_\_\_\_

\_\_\_\_\_

43. An illness, even a minor 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 did P's illness increase the amount of overall stress in your family?

That is, would you say it increased the stress:

1) a great deal;

2) a moderate amount;

3) very little;

4) not at all?

44. 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 \_\_\_\_\_

a. What changes are these? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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

That is, would you say you were:

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

c. Did any of these changes last beyond the period of P's illness?

Yes: \_\_\_\_\_ No \_\_\_\_\_

If so, which ones? \_\_\_\_\_  
\_\_\_\_\_

45. In general, how well do you think you handled  P's  illness? That is, would you say you handled it:

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

a. In our original interview you mentioned \_\_\_\_\_ as a major change in your life before  P  was born. Do you think this (these) event(s) helped you in any way to deal with  P  when he/she was ill?

Yes: \_\_\_\_\_ No: \_\_\_\_\_

45 b. Do you think this (these) previous event(s) make it more difficult to deal with P's illness? Yes: \_\_\_\_\_ No: \_\_\_\_\_

45 c. In our original interview, you also mentioned \_\_\_\_\_ as a major change in your life after P was born. Do you think this helped you in any way to deal with P's illness? Yes: \_\_\_\_\_ No: \_\_\_\_\_

45 d. Do you think this made it more difficult to deal with P's illness?  
Yes: \_\_\_\_\_ No: \_\_\_\_\_

46. 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 was disrupted in your family when P became ill.

That is, tell me it it's been:

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

\_\_\_ 1) your spouse's 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

\_\_\_ 8) the time your family plays together, goes on outings, etc.

\_\_\_ 9) the time you have to be by yourself.

47. I am going to read you some things related to P's illness that could have produced stress for you. For each thing, please tell me if it was:

- 1) very stressful;
- 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. effect on your lifestyle
- \_\_\_\_\_ 5. work interfered with
- \_\_\_\_\_ 6. concern about your husband
- \_\_\_\_\_ 7. following P's medication schedule
- \_\_\_\_\_ 8. going to the clinic
- \_\_\_\_\_ 9. concern about P's recovery

48. 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 49-52 as soon as you've completed the interview, but not in the presence of the respondent.)

49. How open and cooperative was the R?

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

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

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

51. 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

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

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