

all this  
can be filled  
in by  
interviewer

Family's name \_\_\_\_\_

Respondent's name \_\_\_\_\_

Patient's medical record number \_\_\_\_\_

Date of interview \_\_\_\_\_

Interviewer's name \_\_\_\_\_

FAMILY INTERACTION QUESTIONNAIRE

Introduction

This questionnaire examines the effects on the family of illness and different family responses to illness. For the purposes of this study, please consider the child you have brought to clinic as the ill member of the family. There are no right or wrong answers, we simply want to learn more about how families and illness interact. Please answer as accurately and honestly as possible. All forms will remain anonymous to the extent provided by law. Thank you very much for your cooperation.

Double space

I - PARENTAL RESPONSE

- A. Illness in one family member can often have an effect on other family members. Please describe how your child's most recent illness episode affected you.

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- B. Listed below are some common feelings which parents have reported in response to the stress of illness in their child. Please rate the extent to which these statements are true for you during your child's last illness.

- |            |          |          |            |              |
|------------|----------|----------|------------|--------------|
| 1          | 2        | 3        | 4          | 5            |
| Not at all | Slightly | Somewhat | Moderately | A great deal |
- \_\_\_ a. I felt guilty when my child became ill.
- \_\_\_ b. I felt able to cope when my child became ill.
- \_\_\_ c. I felt anxious when my child became ill.
- \_\_\_ d. I felt I might have done more to prevent or minimize my child's illness.
- \_\_\_ e. I felt overwhelmed by the responsibility of caring for my sick child.
- \_\_\_ f. I felt more loving than usual toward my child during this illness.
- \_\_\_ g. I felt more indulgent than usual toward my child during this illness.
- \_\_\_ h. I felt withdrawn from my child during this illness.
- \_\_\_ i. I felt important during this illness because my child really needed me.
- \_\_\_ j. I felt more tired and fatigued while my child was ill.
- \_\_\_ k. Once my child had recovered, I felt depressed and let down.
- \_\_\_ l. At times, I felt like rejecting the doctor's interpretation of my child's illness.
- \_\_\_ m. I felt my own needs sometimes were neglected during my child's illness.

- C. People who are experiencing a more than usual degree of stress in their lives respond in a variety of ways. Did you notice an increase in any of the following during your child's last illness?

Behavior (please answer "yes" or "no")

- a. Smoking
- b. Eating
- c. Drinking (alcoholic beverage)
- d. Using aspirin
- e. Using sedatives, tranquillizers
- f. Stomach aches, diarrhea
- g. Headaches
- h. Other physical symptoms
- i. Other (Please state) \_\_\_\_\_

If you answered yes to any of the above, please explain.

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Now, go back to the original list, and for those items to which you responded "yes," please rate the degree of increase according to the following scale:

1	.2	3
Slight increase	Moderate increase	Major increase

D. Parents try to cope with a child's illness in a variety of ways. How did you try to cope with your child's illness?

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Please rate the extent to which you engaged in any of these coping mechanisms during your child's last illness.

*This format is confusing unless an interviewer specifically understands to include only those items with a "yes."*

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

- a. I tended to minimize the seriousness of the illness.
- b. I tended to exaggerate the seriousness of the illness.
- c. I tried to seek information about the illness.
- d. I tended to request reassurance and emotional support from my doctor.
- e. I tended to request reassurance and emotional support from family and friends.
- f. I tried to learn about specific methods of treatment.
- g. I tended to think about the different possible outcomes (what if child gets sicker, what if child gets well)
- h. I tended to engage in activities (cleaning house, paying bills, doing errands)
- i. Other (please state): \_\_\_\_\_

*Some people may do both at times depending on the situation, their own personal level - whether they are attempting to manipulate others*

E. Please describe anything you feel you did particularly well in terms of coping with your child's most recent illness episode.

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F. Please describe anything you feel you did particularly poorly in terms of coping with your child's most recent illness episode.

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A. Please describe how your child reacted to his/her most recent illness episode.

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B. Below are some ways children often act in response to illness. Please rate the extent to which these statements were characteristic of your child during his/her most recent illness episode.

- a. My child seemed angry at becoming ill.
- b. My child appeared despondent and sad.
- c. My child appeared withdrawn and detached.
- d. My child did not seem different than usual during this illness.
- e. My child was more irritable than usual.
- f. My child appeared anxious and fearful.
- g. At times, my child seemed to enjoy being sick.
- h. My child's reaction to medical treatment was generally uncooperative.
- i. My child sometimes used his/her symptoms to get special treatment.
- j. My child seemed to blame me for "allowing" him/her to become sick.
- k. My child's self-esteem seemed to suffer when he/she was sick.
- l. My child seemed to feel "punished" by having become sick.
- m. Other (please state): \_\_\_\_\_

C. Children often use specific behaviors to help them deal with an illness. What unusual behaviors, if any, did you notice in your child?

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*more than when well*  
*used*  
1

D. Did you feel your child used any of the following behaviors to help him/her cope with this past illness?

Behavior (please circle "yes" or "no")

- Sleep.....yes/no
- Watch TV.....yes/no
- Play with favorite toys.....yes/no
- Eat favorite food.....yes/no
- Suck thumb, pacifier.....yes/no
- Hold blanket, stuffed animal.....yes/no
- Talk about sickness.....yes/no
- Stay near mother.....yes/no

Other (please state): \_\_\_\_\_

*Remember?*

E. Children also often experience disturbances in their usual behavior patterns as a result of illness. What changes, if any, did you observe in your child?

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F. Did your child exhibit any of these specific behavioral changes when he/she was sick?

Behavior (please circle "yes" or "no")

- Sleep disturbances.....yes/no
- Nightmares.....yes/no
- Fears.....yes/no
- Regression to bottle.....yes/no
- Regression in speech.....yes/no
- Regression in toilet training.....yes/no
- Became clinging.....yes/no
- Afraid to be alone.....yes/no
- Afraid to go to bed.....yes/no
- Feeding problems.....yes/no
- More babyish.....yes/no
- Jealous of siblings.....yes/no
- Increased aggressiveness.....yes/no
- Played more with toys.....yes/no
- Played less with toys.....yes/no
- Cold toward parents.....yes/no
- Unusually affectionate toward parents yes/no
- Stopped dressing self.....yes/no
- Lower frustration tolerance.....yes/no

Other (please state): \_\_\_\_\_

III - OVERALL FAMILY RESPONSE

6.

- A. Families react to the stress of illness in different ways. How would you describe the family's reaction to your child's most recent illness episode?

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- B. In particular, please rate the extent to which the following statements were characteristic of your family during the child's last illness:

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

- a. There seemed to be more tension than usual in the family.
- b. There appeared to be more closeness than usual in the family.
- d. Family members tended to avoid the sick child.
- e. Sometimes the needs of other family members were neglected during the child's illness.
- f. Our family was no different than usual during the child's sickness.
- g. As the child began to recover, it was hard for our family to shift from seeing the child as sick to seeing the child as well.

- C. Illness can effect a family in many ways. How did the child's illness affect your family?

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- D. Specifically, to what extent did you notice disruption of any of the following areas:

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

- a. father's work
- b. mother's work
- c. sibling school attendance
- d. family meals
- e. family social activities
- f. contact with family friends
- g. finances (eg., family budget)
- h. time with spouse
- i. time with other siblings
- j. health-related family activities (exercise, sports)
- k. other (please explain) \_\_\_\_\_

E. Illness in the family is often considered a stressful event. However, the degree of stress caused by a particular illness incident varies considerably from family to family. In your estimation, to what extent did you child's illness episode increase the amount of stress in your family?

- |            |          |          |            |              |
|------------|----------|----------|------------|--------------|
| 1          | 2        | 3        | 4          | 5            |
| Not at all | Slightly | Somewhat | Moderately | A great deal |

F. At the time of your child's last illness, please list 5 areas which were sources of stress in your family. Then number the list from least stressful (1) to most stressful (5), and indicate where the child's illness would fall on the list. - *Including the child's illness in the 5 >*

*This format is confusing  
A skilled interviewer could help with this one*

- a. \_\_\_\_\_
- b. \_\_\_\_\_
- c. \_\_\_\_\_
- d. \_\_\_\_\_
- e. \_\_\_\_\_

G. Even when an illness is experienced by the family as stressful, families differ as to which aspects of the illness contributed most to the feelings of stress. In your opinion, to what extent did the following produce feelings of stress in the family during the child's sickness?

- |            |          |          |            |              |
|------------|----------|----------|------------|--------------|
| 1          | 2        | 3        | 4          | 5            |
| Not at all | Slightly | Somewhat | Moderately | A great deal |
- a. additional housekeeping chores
  - b. sleepless nights
  - c. additional expenses
  - h. concern about child's health
  - i. concern about siblings
  - j. concern about spouse



- d. lifestyle interfered with
- e. work interfered with
- f. coordinating healthcare
- g. logistical problems

- k. following the child's medication schedule
- l. returning for follow-up visits
- m. other (please explain):  
\_\_\_\_\_

H. Families have different ways of interacting about a child's sickness. In particular, the ways in which family members communicate <sup>with</sup> each other about the illness varies. Please note which, if any, of the following interactions about your child's most recent illness occurred in your family.

Behavior (please circle "yes" or "no")

- I discussed the child's illness with the family as a whole.....yes/no
- I discussed the illness separately with each family member.....yes/no
- I discussed the illness only with the child him/herself.....yes/no
- I discussed the illness only with my spouse.....yes/no
- I discussed the illness only with the child's brothers  
and/or sisters.....yes/no
- I did not discuss the illness with other family members.....yes/no

*These may both occur!*

I. Sometimes family members' roles 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. If yes, please describe.

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J. Sometimes when there is an illness in the household, other family members also become sick, either with a similar or a different illness. Did this happen in your family? If yes, please elaborate.

Family Member	Nature of Illness	Duration	Consequences (missed work, school etc)
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K. Please rate overall how well you feel your family coped with this most recent illness episode.

1	2	3	4	5
Not at all well	Slightly well	Somewhat well	Moderately well	Very well

L. What were effective ways your family used to cope with this past illness episode?

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M. What were ineffective ways your family used to try to cope with this past illness episode? - *Some people may not be able to recognize these*

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*It will be interesting to see the responses*

N. Which member(s) was (were) primarily involved in caring for the sick child? (Please list.)

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O. Which family member had primary psychological responsibility for the sick child?

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P. Many people are able to look beyond their immediate families for support in dealing with a sick child. Are there people who constitute such a network of support for your family? If yes, please specify who they are:

- Grandparents
- Neighbors
- Other relatives
- Daycare
- Friends
- Paid strangers (housekeeper, babysitters)
- Church

Q. Who in your family has primary responsibility for coordinating this network and putting it into operation when necessary?

*This language may be too sophisticated. May need to give an example of how calls my mother for help, & she tells every else.*

R. Please describe how this network functioned to support you during your child's most recent illness episode.

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S. Please rate the extent to which you feel this network was effective in terms of helping you deal with your sick child?

- |            |          |          |            |              |
|------------|----------|----------|------------|--------------|
| 1          | 2        | 3        | 4          | 5            |
| Not at all | Slightly | Somewhat | Moderately | A great deal |

T. What are the usual health-care responsibilities of this network?

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U. Which of the following functions are sometimes assumed by members of this network? (please circle one)

*← Why only one choice - see next page*

FUNCTION (please circle one) - *for each statement*

- Staying with sick child.....sometimes/often/never
- Taking child to doctor.....sometimes/often/never
- Obtaining medications for child.....sometimes/often/never
- Cooking, cleaning, housekeeping.....sometimes/often/never
- Providing emotional support.....sometimes/often/never
- Caretaking of siblings.....sometimes/often/never
- Other (please explain): \_\_\_\_\_

IV PARENT-PARENT INTERACTIONS

A. Relationships between husband and wife are sometimes also affected by a child's illness. Please describe any ways in which you felt your child's most recent illness affected your relationship with your spouse.

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B. Specifically, please rate the extent to which the following statements were true for you and your spouse during your child's most recent illness.

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

- \_\_\_ a. My interactions with my spouse became more supportive (talked more about our feelings, expressed concern for each other's well-being)
- \_\_\_ b. My interactions with my spouse became more instrumental (talked more about who would take care of which additional responsibilities)
- \_\_\_ c. The amount of affectionate words and gestures between me and my spouse increased.
- \_\_\_ d. The degree of nonverbal tension between me and my spouse increased.
- \_\_\_ e. The amount of quarreling between me and my spouse increased. *decreased?*
- \_\_\_ f. My spouse and I spent less time than usual talking to each other during our child's illness.
- \_\_\_ g. At times, my spouse appeared to resent the amount of time I devoted to caring for the sick child.

C. At times, the stress of a sickness in the family can effect the sexual relationship between husband and wife. What effect, if any, did your child's sickness have on your sexual activities with your spouse?

Frequency of sexual activity: Increased Decreased Stayed the same

\_\_\_\_\_

D. Sometimes husband and wife have different reactions to the same sickness in their child. Did you and your spouse have the same or different attitudes toward this past sickness? If different, please describe the differences.

Degree of concern.....same/different

\_\_\_\_\_

Consultation with physician.....same/different

\_\_\_\_\_

Implications for child's behavior.....same/different

\_\_\_\_\_

Implications for family's behavior.....same/different

\_\_\_\_\_

E. Sometimes husband and wife also have different ideas about how a specific illness in their child should be treated. Did you and your spouse agree or disagree on the treatment of this past illness episode in your child? If you disagreed, please describe the differences.

Point of seeking out physician.....same/different

\_\_\_\_\_

Need for medication.....same/different

\_\_\_\_\_

Definition of wellness.....same/different

\_\_\_\_\_

*Remind interview to probe for "How different aspect of response"*

*←*

F. Which parent was the decision-maker regarding treatment?

Mother      Father      Both      Neither

G. Please rate the extent to which communication with your spouse about the child's illness included any of the following components:

- |                                                                                                                              | 1          | 2        | 3        | 4          | 5            |
|------------------------------------------------------------------------------------------------------------------------------|------------|----------|----------|------------|--------------|
|                                                                                                                              | Not at all | Slightly | Somewhat | Moderately | A great deal |
| <input type="checkbox"/> a. Seeking support, reassurance                                                                     |            |          |          |            | ✓            |
| <input type="checkbox"/> b. Giving information                                                                               |            |          |          |            |              |
| <input type="checkbox"/> c. Seeking advice about treatment                                                                   |            |          |          |            |              |
| <input type="checkbox"/> d. Giving support, reassurance                                                                      |            |          |          |            | ✓            |
| <input type="checkbox"/> e. Discussing child's <sup>physical, emotional,</sup> "response" to <sup>behavioral</sup> treatment |            |          |          |            | ✓            |
| <input type="checkbox"/> f. Medical-related expenses                                                                         |            |          |          |            |              |
| <input type="checkbox"/> g. Logistical problems                                                                              |            |          |          |            | ✓            |
| <input type="checkbox"/> h. Expressing feelings                                                                              |            |          |          |            | ✓            |
| <input type="checkbox"/> i. Expressing worries, concerns                                                                     |            |          |          |            | ✓            |
| <input type="checkbox"/> j. Asking for help                                                                                  |            |          |          |            |              |
| <input type="checkbox"/> k. Other (please explain): _____                                                                    |            |          |          |            |              |

*How do these differ?*

*may need to explain some of these terms. See items marked with a check.*

V PARENT-PATIENT INTERACTIONS

A. What effect, if any, did the child's most recent illness have on your relationship with him/her?

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B. Specifically, to what extent were the following statements true descriptions of your interactions with your child when he/she was ill:

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

- a. I spent more time than usual with my child.
- b. I spent less time than usual with my child.
- c. The amount of affectionate words and gestures between my child and me increased during his/her sickness.
- d. The amount of quarreling and fighting between my child and me increased during his/her illness. *- or decreased -*  
*should ask both increases & decrease*
- e. I treated my child the same as usual during his/her illness.
- f. I did special "nice" things for my child during his/her illness (brought presents, made special foods etc).

C. Parents have different ways of telling a child about his/her illness. Did you talk about this most recent illness episode with the child? If yes, please rate the extent to which you focused on the following:

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

- a. child's feelings
- b. your feelings
- c. information about illness
- d. instruction about self-care during illness (medicines, rest, clothing etc.)
- e. reassurance about illness
- f. other (please explain): \_\_\_\_\_

D. Parents often have many emotional reactions in response to an illness in their child. If you experienced any of the feelings listed below, to what extent did you communicate them to your child, either directly or indirectly:

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

*↑*  
*no have to*  
*just the*  
*words*  
*"indirectly"*

- a. frustration
- b. irritation, annoyance
- c. helplessness
- d. fear
- e. confident about your ability to cope

#### VI PARENT-SIBLING INTERACTIONS

- A. In what ways, if any, did the child's most recent illness affect your relationship with your other children?

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- B. Specifically, to what extent would the following statements describe your relationship with your other children during your child's most recent illness episode:

1	2	3	4	5
Not at all	Slightly	Somewhat	Moderately	A great deal

- a. My relationship with my other children became more business-like.
- b. My relationship with my other children became more demanding.
- c. My relationship with my other children became more loving.
- d. I spent more time than usual with my other children,
- e. During child's sickness, the amount of affectionate words and gestures between me and my other children increased.
- f. During my child's sickness, the amount of quarreling and fighting between me and my other children increased.
- g. The other children in the family sometimes resented the amount of attention given to the sick child.
- h. The other children seemed to feel somehow they were responsible for the child's sickness.



- C. At times illness in one child can have an effect on other children in the family as well. Did you notice any effect on siblings during the child's most recent illness episode? (If yes, please explain).

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- D. Specifically, indicate to what extent ~~if any~~ you observed the following changes in siblings of the sick child:

	1	2	3	4	5
	Not at all	Slightly	Somewhat	Moderately	A great deal

\_\_\_ a. school problems

\_\_\_ b. tearfulness

\_\_\_ c. disturbed eating habits

\_\_\_ d. aggressiveness

\_\_\_ e. sleeping problems

\_\_\_ f. physical complaints (please specify):

\_\_\_ g. more clinging than usual

\_\_\_ h. more babyish than usual

\_\_\_ i. more withdrawn than usual

\_\_\_ j. more independent than usual

\_\_\_ k. more helpful than usual

\_\_\_ l. more loving than usual

\_\_\_ m. more unhappy than usual

\_\_\_ n. felt less good about himself/herself than usual

\_\_\_ o. other (please explain): \_\_\_\_\_

E. Parents have different ways of telling siblings about a child's illness. Did you talk to your other children about the patient's most recent illness episode?      Yes      No. If yes, to what extent did communication about the sick child with his/her siblings focus on any of the following areas:

	1	2	3	4	5
	Not at all	Slightly	Somewhat	Moderately	A great deal
<u>    </u>	a. seeking support, reassurance				
<u>    </u>	b. giving information				
<u>    </u>	c. seeking advice				
<u>    </u>	d. giving support, reassurance				
<u>    </u>	e. expressing feelings				
<u>    </u>	f. expressing worries, concerns				
<u>    </u>	g. discussing child's response to treatment				
<u>    </u>	h. discussing medical expenses				
<u>    </u>	i. discussing logistical problems				
<u>    </u>	j. asking for help				
<u>    </u>	k. other (please explain): _____				

*Who is the subject of these statements, the mother or the sibling. We need to specify in order to get consistent answers. Also we may need to further clarify some of the terms mark with a check.*

*How do these differ?*

F. Sometimes sickness in one child can influence the way other children in the family feel themselves. For example, when Susan is ill, Peter seems to like himself less well. Do you think this was true in your family? If yes, please explain in what way.

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VII PATIENT-SIBLING INTERACTIONS

- A. Sometimes sickness in one child can affect the way he/she interacts with other children in the family. Did you notice any differences in the ways your children related to each other during this last illness episode? If so, please describe.

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- B. Specifically, please rate the extent to which the following statements appeared to describe your child and his/her siblings during the last illness episode:

	1	2	3	4	5
	Not at all	Slightly	Somewhat	Moderately	A great deal

- \_\_\_ a. During the child's sickness, the amount of friendly play between patient and siblings increased.
- \_\_\_ b. During the child's sickness, the amount of quarreling and fighting between patient and siblings increased.
- \_\_\_ c. Siblings seemed to avoid the child during the last illness.
- \_\_\_ d. Siblings seemed to spend more time than usual with the child.
- \_\_\_ e. Siblings seemed to exhibit more caretaking than usual toward the sick child.
- \_\_\_ f. Siblings appeared to punish the child for being sick. *may need to clarify term. E.g. do siblings punish the sick sibling?*
- \_\_\_ g. Siblings appeared to make "special allowances" for the child because of sickness. *the sibling?*

- C. Did you observe your sick child talking about this most recent illness episode with his/her siblings? If yes, how did the child explain this illness?

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How did the siblings respond?

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VIII - OUTCOME

Please note which of the following, if any, occurred during or after your child's most recent illness:

OUTCOME (please circle "yes" or "no")

- Additional office visits to physician.....yes/no
- Phone contacts with physician.....yes/no If yes, how many:
- Additional medication prescribed.....yes/no
- Medical referral made.....yes/no
- Child hospitalized.....yes/no
- Other members of family became ill.....yes/no
- Child developed other health problems.....yes/no
- Child evidenced behavioral problems at home....yes/no
- Child experienced social, behavioral problems on returning to school.....yes/no
- Siblings experienced school problems.....yes/no
- Siblings had behavioral problems at home.....yes/no
- Recovery was uneventful.....yes/no

*← additional to what?*

If you answered yes to any of the above, please give details below.

*A better format for the above section would be*

*Additional office visits ... yes no*

*If yes, explanation*

*Phone contacts with physician yes no*

*If yes, explanation*

*Medical Referral made yes no*

*If yes, explanation*

*etc*

Need space for

Patient's Name  
Medical Record #

Physician's Name

Date questionnaire completed

PHYSICIAN QUESTIONNAIRE

1. Rate your overall impression of how you feel this family is coping with the child's current illness.

1	2	3	4	5
Not at all well	Slightly well	Moderately well	Well	Very well

2. If you are previously acquainted with this family, how would you rate the family's response to this illness as compared to other illnesses experienced by the same child in the past?

1	2	3	4	5
worse		same		better

3. In your estimation, what is this family's greatest strength in coping with the child's current illness? \_\_\_\_\_

4. In your estimation, what is this family's greatest weakness in attempting to cope with the child's current illness? \_\_\_\_\_

5. How well do you feel the family will follow through on the medical regimen for the patient you outlined during this treatment session?

1	2	3	4	5
Not at all		Moderately		Very well

6. Do you feel the child was brought to the clinic unnecessarily?

1	2	3	4	5
Not at all		Somewhat		Completely

7. Do you feel the parent asked for medicines or other treatment unnecessarily?

1	2	3	4	5
Not at all		Somewhat		Completely

8. Do you feel the child should have been brought for treatment sooner?

1	2	3	4	5
Not at all		Moderately		A great deal

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

1	2	3	4	5
Not at all		Moderately		A great deal

Physician Questionnaire (continued) 2.

10. In your estimation, do you perceive the parent (or other family members) to be highly stressed by the child's current illness?

1	2	3	4	5
Not at all		Moderately		A great deal

11. Please estimate in days the anticipated duration of the child's current illness episode: \_\_\_\_\_

12. Please estimate to what extent you anticipate that the resolution of this particular illness episode will be uneventful and follow a normal course.

1	2	3	4	5
Uneventful		Moderately Uneventful		Many complications

What complications, if any, do you anticipate? \_\_\_\_\_

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Family and Illness Questionnaire  
Coping Styles

This questionnaire examines the effects on the family of acute minor illness and different family coping styles in response to illness. For the purposes of this study, please consider that your child is the ill member of the family. There are no right or wrong answers, we simply want to learn more about how families and illness interact. Please answer as accurately and honestly as possible. All forms will remain completely anonymous. Thank you very much for your cooperation.

QUESTIONNAIRE

Demographics

Please list members of your family:

	Sex	Age	Citizenship	Ethnic origin
Self				
Spouse				
Children				

This is currently my: 1st      2nd      3rd      marriage (please circle one).

My spouse and I have been married: 1-5yrs      5-10yrs      10-15yr  
 (please circle one)      more than 15 yrs.

Occupation: \_\_\_\_\_

Education: \_\_\_\_\_

Income (yearly/combined): \_\_\_\_\_

Any congenital or genetic diseases that you know of in your family?

yes \_\_\_\_ no \_\_\_\_

If so, please list: \_\_\_\_\_

Please note shared or separate sleeping arrangements:

mother: \_\_\_\_\_

father: \_\_\_\_\_

siblings: \_\_\_\_\_

Number of families you know with same age children: \_\_\_\_\_

with older children: \_\_\_\_\_



2.

Amount of contact with extended family (grandparents, other relatives):

phone contact/month: \_\_\_\_\_

visits/year: \_\_\_\_\_

Last remembered illness occurred in child: \_\_\_\_\_ less than one month ago

\_\_\_\_\_ 1-3 months ago

\_\_\_\_\_ 6-12 months ago

\_\_\_\_\_ 3-6 months ago

\_\_\_\_\_ more than 12 months ago

Your best estimate is that you child has: \_\_\_\_\_ less than 1 minor illness per year

\_\_\_\_\_ 1-3 per year

\_\_\_\_\_ 6-9 per year

\_\_\_\_\_ 3-6 per year

\_\_\_\_\_ 9-12 per year

\_\_\_\_\_ more than 12 per year

Are any of your children in school? Specify which and what grades: \_\_\_\_\_

---

---

Are any of your children in daycare? \_\_\_\_\_ How many? \_\_\_\_\_

ages: \_\_\_\_\_ hours per week: \_\_\_\_\_

Are any of your children with a babysitter? \_\_\_\_\_ How many? \_\_\_\_\_

ages: \_\_\_\_\_ hours per week: \_\_\_\_\_

Are any of your children in family daycare? \_\_\_\_\_ How many? \_\_\_\_\_

ages: \_\_\_\_\_ hours per week: \_\_\_\_\_

3.

PARENTAL RESPONSE

When you learn the nature of your child's illness, do you tend to feel: (check as many as appropriate)

_____ relieved	_____ anxious
_____ panicked	_____ able to cope
_____ confused	_____ not able to cope
_____ sad	

Do you tend to feel guilty and blame yourself when your child becomes ill? \_\_\_\_\_

Do you ever feel you might have done more to prevent or minimize your child's illness? \_\_\_\_\_

Do you ever feel angry or resentful toward your child during illness? \_\_\_\_\_

Do you ever feel overwhelmed by the responsibility of caring for your sick child? \_\_\_\_\_

Do you feel more/less loving toward your child during illness? \_\_\_\_\_

Do you feel you are more/less indulgent when your child is sick? \_\_\_\_\_

Do you find yourself smoking more than normal when your child is ill? \_\_\_\_\_

Do you find yourself overeating when your child is sick? \_\_\_\_\_

Do you find yourself drinking alcohol more than normal when your child is ill? \_\_\_\_\_

Do you feel you are able to be accepting of your child's illness? \_\_\_\_\_

Do you tend to use more aspirin (for yourself) when your child is ill? \_\_\_\_\_

Do you find yourself resorting to tranquilizers or sedatives more often when your child is ill? \_\_\_\_\_

Do you ever wish you could exchange places with your sick child? \_\_\_\_\_

Once you are aware your child is ill, do you: (check as many as appropriate)

_____ tend to minimize the seriousness of the disease
_____ tend to exaggerate the seriousness of the disease
_____ seek information about the sickness
_____ request reassurance and emotional support
_____ learn about specific methods of treatment

please continue question on the next page . . .

4.

Continued . . .

\_\_\_\_\_ think about different possible outcomes (what if child gets sicker, what if child gets well)

\_\_\_\_\_ engage in activity (clean house, pay bills, do errands)

Do you ever feel angry or upset with your doctor, nurses or other health personnel when your child is sick? \_\_\_\_\_

Do you ever feel withdrawn from your child during his/her illness? \_\_\_\_\_

Do you ever feel pleased when your child is ill because he/she really needs you? \_\_\_\_\_

Do you ever blame others for your child's illness? \_\_\_\_\_

Do you ever feel more tired and fatigued when your child is ill? \_\_\_\_\_

Do you ever feel helpless when your child is ill? \_\_\_\_\_

Do ever feel depressed or let down once your child has recovered? \_\_\_\_\_

Do you ever feel like rejecting the doctor's interpretation of your child's illness? \_\_\_\_\_

5.

RESPONSE TO ONSET OF ILLNESS

Do you ever wonder initially whether your child is faking or exaggerating symptoms? \_\_\_\_\_

Do you feel the best way to determine whether your child is really sick is: (check one)

- \_\_\_\_\_ your own observations
- \_\_\_\_\_ take to doctor
- \_\_\_\_\_ consult with neighbors
- \_\_\_\_\_ consult with relatives

How do you know when your child is becoming sick?

- \_\_\_\_\_ symptoms (runny nose, fever)      \_\_\_\_\_ whiney
- \_\_\_\_\_ lethargic      \_\_\_\_\_ clinging
- \_\_\_\_\_ loss of appetite      \_\_\_\_\_ don't know

Who is usually first aware that your child is sick:

- \_\_\_\_\_ mother      \_\_\_\_\_ siblings      \_\_\_\_\_ other relative
- \_\_\_\_\_ father      \_\_\_\_\_ grandparent

Do you initially ever try to ignore signs that your child is becoming ill? \_\_\_\_\_

When you are aware your child is ill, your initial response is: (check as many as applicable)

- \_\_\_\_\_ anxiety
- \_\_\_\_\_ relief
- \_\_\_\_\_ increased activity
- \_\_\_\_\_ depression
- \_\_\_\_\_ increased planning

## CHILD RESPONSE

Does your child ever seem angry at becoming ill? \_\_\_\_\_

Does your child ever appear despondent or sad when ill? \_\_\_\_\_

Does your child appear more withdrawn, detached when ill? \_\_\_\_\_

What does your child do to feel better during illness?

_____ sleep	_____ suck thumb, pacifier
_____ watch T.V.	_____ hold blanket, stuffed animal
_____ eat favorite food	_____ stay near mother
_____ play with favorite toys	_____ talk about sickness
_____ other: (describe) _____	

When your child is ill, he/she appears:

_____ calm	_____ anxious
_____ unconcerned	_____ worried
_____ unafraid	_____ fearful
_____ even-tempered	_____ irritable

Does your child exhibit any of these behavioral changes when he/she is sick?

_____ sleep disturbances	_____ becoming clinging
_____ nightmares	_____ afraid to be alone
_____ fears	_____ afraid to go to bed
_____ regression to bottle	_____ feeding problems
_____ regression in speech	_____ more babyish
_____ regression in toilet training	_____ jealous of siblings, children
_____ increased aggressiveness	_____ cold toward parents
_____ plays more with toys	_____ loves parent (you) more
_____ plays less with toys	_____ stops dressing self
_____ increased self gratification (thumbsucking, blanket, masturbation)	_____ lower frustration tolerance

7.

Do you ever feel your child enjoys being sick? \_\_\_\_\_

Your child's reaction to medical treatment is generally cooperative/uncooperative.

Do you ever feel your child's self-esteem suffers when he/she is sick? \_\_\_\_\_

Do you ever feel your child uses his/her symptoms to manipulate special consideration? \_\_\_\_\_

Do you ever feel your child blames you for "allowing" him/her to become sick? \_\_\_\_\_

Do you think your child ever feels "punished" for being sick? \_\_\_\_\_

8.

OVERALL FAMILY RESPONSE

Which of the indicators listed below does your family use in recognizing that your child has made the transition from sick to well?

\_\_\_\_\_ symptom - free                      \_\_\_\_\_ dresses self  
\_\_\_\_\_ more independent                      \_\_\_\_\_ better appetite  
\_\_\_\_\_ more interactive                      \_\_\_\_\_ resumes household responsibilities  
\_\_\_\_\_ more energy  
\_\_\_\_\_ other (specify): \_\_\_\_\_

Do you tend to discuss the course of your child's illness with the family as a whole? \_\_\_\_\_

Do you tend to discuss the illness separately with each family member? \_\_\_\_\_

Do you tend to discuss the illness:

\_\_\_\_\_ with patient only                      \_\_\_\_\_ with siblings only  
\_\_\_\_\_ with spouse only

To what extent does a child's illness interfere with the family's outside activities?

\_\_\_\_\_ outside events cancelled  
\_\_\_\_\_ outside people not seen

To what extent does there tend to be more tension in your family when a child is ill? \_\_\_\_\_

To what extent does there tend to be more closeness than normal in your family when a child is ill? \_\_\_\_\_

In your family, when a child is sick do family members tend to avoid that child?  
\_\_\_\_\_

In your family, when a child is sick, do family members tend to give that child special attention and consideration? \_\_\_\_\_

When one child is ill, do other members of the family also develop symptoms?  
\_\_\_\_\_

9.

Who else is most likely to become sick when there is a sick child in the house? \_\_\_\_\_

In your family, is the sick child allowed extensive contact with other family members? \_\_\_\_\_

In your family, is the sick child isolated from other family members (i.e. uses separate dishes, stays in room). \_\_\_\_\_

What, if any, redistributions of family roles occur when your child is sick:

\_\_\_\_\_ none      \_\_\_\_\_ slight      \_\_\_\_\_ moderate      \_\_\_\_\_ very great  
\_\_\_\_\_ spouse takes over more/less housekeeping functions  
\_\_\_\_\_ spouse takes over more/less caretaking functions  
\_\_\_\_\_ siblings take over more/less housekeeping functions  
\_\_\_\_\_ siblings take over more/less caretaking functions  
\_\_\_\_\_ other (please specify): \_\_\_\_\_

Do you ever feel that when one child is sick in your family, other family members tend to be neglected? \_\_\_\_\_

Do you ever feel your own needs are neglected during your child's illness? \_\_\_\_\_

Do you feel it is easy/hard for your family to shift from seeing the child as sick as seeing the child as well? \_\_\_\_\_

When your child is sick, which of these describes your family's attitude: (check as many as applicable)

\_\_\_\_\_ The child is exempt from normal responsibilities  
\_\_\_\_\_ The child is not blamed for dyssocial behavior  
\_\_\_\_\_ The child is not expected to care for self  
\_\_\_\_\_ The child is expected to want to get better

What are effective ways your family has of responding to illness? \_\_\_\_\_  
\_\_\_\_\_

What are maldaptive ways your family has of responding to illness? \_\_\_\_\_  
\_\_\_\_\_

Please rate how well your family copes with minor illness.

\_\_\_\_\_ not at all well      \_\_\_\_\_ moderately well      \_\_\_\_\_ very well  
\_\_\_\_\_ slightly well      \_\_\_\_\_ well



10.

ROLE OF EXTENDED FAMILY COMMUNITY

Which of the following statements best describes your family:

- Our family is heavily involved in community organizations and functions
- Our family is closely tied to relatives, extended family and friends.
- Our family is close, but has little contact with the outside community or extended family.
- Our family is not close: we each go our separate ways.

Do you ever discuss your feelings about your child's illness with relatives (specify which ones)? with friends? \_\_\_\_\_

Do you ever feel you are pressured by neighbors, strangers, society in general about how to care for your child when he/she is sick? \_\_\_\_\_

Our family is most comfortable turning to friends and family /professionals and experts for medical advice? \_\_\_\_\_

for support? \_\_\_\_\_

Do you ever discuss your child's illness with friends and neighbors? \_\_\_\_\_ with relatives? \_\_\_\_\_

Do you ever consult a religious figure (minister, priest, faith healer) about your child's illness? \_\_\_\_\_

Communication with your relatives about your child's illness tends to focus on which of the following areas: (check as many as applicable)

- giving information
- seeking advise about treatment
- giving support, reassurance
- expressing worries, concerns
- discussing child's response to treatment
- discussing medical expenses
- discussing logistical problems
- asking for help

PARENT - PATIENT INTERACTIONS

To what extent do you tend to talk to your child about his or her illness?

\_\_\_\_\_

To what extent to you tend to focus on:

\_\_\_\_\_ feelings  
\_\_\_\_\_ information  
\_\_\_\_\_ instruction  
\_\_\_\_\_ reassurance  
\_\_\_\_\_ other

How do you explain illness to the child?

\_\_\_\_\_ germs, virus  
\_\_\_\_\_ not enough rest  
\_\_\_\_\_ something you ate  
\_\_\_\_\_ bad child  
\_\_\_\_\_ other (specify): \_\_\_\_\_

If you feel angry or frustrated about the child's illness, do you ever share these feelings with the child? \_\_\_\_\_

If you feel frightened by the child's illness, do you share these feelings with the child? \_\_\_\_\_

12.

PARENT - PARENT INTERACTIONS

During child's illness, does your relationship with your spouse become:

- \_\_\_\_\_ more business-like
- \_\_\_\_\_ more loving
- \_\_\_\_\_ more supportive
- \_\_\_\_\_ more instrumental

Do you ever notice a decrease in sexual activities with your spouse then your child is sick? \_\_\_\_\_

During your child's illness, amount of affectionate words and gestures between you and your spouse:

- \_\_\_\_\_ increases          \_\_\_\_\_ decreases          \_\_\_\_\_ remains the same

During child's sickness, amount of quarreling, verbal tension between you and your spouse:

- \_\_\_\_\_ increases          \_\_\_\_\_ decreases          \_\_\_\_\_ remains the same

Do you discuss the course of the illness periodically with your spouse? \_\_\_\_\_

Do you feel you and your spouse spend more time/less time than usual talking during your child's illness? \_\_\_\_\_

Do you feel your spouse ever resents the amount of time you devote caring for the sick child? \_\_\_\_\_

Do you feel you and your spouse have the same attitude toward sickness? \_\_\_\_\_

If no, the differences are the following:

- \_\_\_\_\_ you are more concerned about illness
- \_\_\_\_\_ spouse is more concerned about sickness.
- \_\_\_\_\_ you believe doctor should always be consulted
- \_\_\_\_\_ spouse believes doctor should always be consulted
- \_\_\_\_\_ you are more fatalistic about illness
- \_\_\_\_\_ spouse is more fatalistic about illness
- \_\_\_\_\_ other (specify): \_\_\_\_\_

13.

Do you feel you and your spouse agree on treatment of illness in your child? \_\_\_\_\_

If no, the differences are the following:

- \_\_\_\_\_ you want to take child to physician sooner than does spouse
- \_\_\_\_\_ spouse wants to take child to physician sooner than you
- \_\_\_\_\_ you tend to be suspicious of medicines
- \_\_\_\_\_ spouse tends to be suspicious of medicines
- \_\_\_\_\_ you believe child can cure self
- \_\_\_\_\_ spouse believes child can cure self
- \_\_\_\_\_ other (specify): \_\_\_\_\_

Communication with your spouse about child's illness includes which of the following components:

- |                                                |                                    |
|------------------------------------------------|------------------------------------|
| _____ seeking support, reassurance             | _____ medical-related expenses     |
| _____ giving information                       | _____ logistical problems          |
| _____ seeking advise about treatment           | _____ expressing feelings          |
| _____ giving support, reassurance              | _____ expressing worries, concerns |
| _____ discussing child's response to treatment | _____ asking for help              |

When your child becomes ill, does your spouse generally:

- \_\_\_\_\_ express anger toward you
- \_\_\_\_\_ behave supportively toward you
- \_\_\_\_\_ act as the decision maker regarding treatment
- \_\_\_\_\_ other: \_\_\_\_\_

## PARENT - SIBLINGS INTERACTIONS

Does your relationship with your other children during your child's illness become:

\_\_\_\_\_ more perfunctory                      \_\_\_\_\_ more loving  
 \_\_\_\_\_ more demanding                      \_\_\_\_\_ more nurturing

During child's sickness, amount of affectionate words and gestures between you and other children:

\_\_\_\_\_ Increases                      \_\_\_\_\_ decreases                      \_\_\_\_\_ remains the same

During child's sickness, amount of quarreling, fighting between you and other children:

\_\_\_\_\_ increases                      \_\_\_\_\_ decreases                      \_\_\_\_\_ remains the same

Indicate to what extent you observe the following changes in siblings of the sick child:

_____ school problems	_____ more clinging
_____ tearfulness	_____ more babyish
_____ disturbed eating habits	_____ more withdrawn
_____ aggressiveness	_____ more independent
_____ sleeping problems	_____ more helpful
_____ physical complaints	

Do you feel other children in your family resent the amount of attention given the sick child?

Do you ever talk about the sick child with his/her siblings?

Communication about your sick child with his/her siblings tends to focus on which of the following areas:

_____ seeking support, reassurance	_____ expressing worries, concerns
_____ giving information	_____ discussing child's response to treatment
_____ seeking advise	_____ discussing medical expenses
_____ giving support, reassurance	_____ discussing logistical problems
_____ expressing feelings	_____ asking for help

15.

During child's sickness, the amount of friendly play between patient and siblings:

\_\_\_\_\_ increases      \_\_\_\_\_ decreases      \_\_\_\_\_ remains the same

During child's illness, amount of quarreling, fighting between patient and siblings:

\_\_\_\_\_ increases      \_\_\_\_\_ decreases      \_\_\_\_\_ remains the same

16.

CARE TAKING

Which parent (m,f) is responsible for these day-to-day aspects of your child's health?

- \_\_\_\_\_ routine doctor visits
- \_\_\_\_\_ immunizations
- \_\_\_\_\_ nutrition
- \_\_\_\_\_ dental checks
- \_\_\_\_\_ medical emergencies

Who is primarily responsible (mother, father, grandparent, relative, neighbor, hired help, no one, equal between parents) for the day-to-day care of the sick child?

- \_\_\_\_\_ staying with sick child
- \_\_\_\_\_ giving medication
- \_\_\_\_\_ taking to doctor
- \_\_\_\_\_ filling prescriptions

Who makes decisions about day-to-day treatment of child:

- |                    |                  |                             |
|--------------------|------------------|-----------------------------|
| _____ mother       | _____ relative   | _____ equal between parents |
| _____ father       | _____ neighbor   | _____ no one                |
| _____ grandparents | _____ hired help | _____ other: _____          |

Would you like your spouse to be more involved in the care of a sick child?

- \_\_\_\_\_ yes                      \_\_\_\_\_ NO                      \_\_\_\_\_ don't know

If you are a working parent, to what extent do you feel your employment interferes with your child's health care. \_\_\_\_\_

Do you ever send your child to school (daycare, babysitter) with a cold? \_\_\_\_\_

Do you ever send your child to school (daycare, babysitter) with a fever? \_\_\_\_\_

Do you like to keep your child at home until he/she is completely well? \_\_\_\_\_

17.

Do you allow your child to play outside when he/she is ill but without fever? \_\_\_\_\_

Do you allow your child to play outside with a fever? \_\_\_\_\_

Does your child ever get special treats (new toys, favorite food) when sick?

\_\_\_\_\_



18.

ATTITUDES TOWARD HEALTH AND ILLNESS

Which of the following statements best describes the attitude you wish your child to develop toward physical illness:

- |                                                         |                                              |
|---------------------------------------------------------|----------------------------------------------|
| <input type="checkbox"/> 1) doctor will help you        | <input type="checkbox"/> 5) 1 & 3            |
| <input type="checkbox"/> 2) parent will help you        | <input type="checkbox"/> 6) 2 & 3            |
| <input type="checkbox"/> 3) you can often help yourself | <input type="checkbox"/> 7) all of the above |
| <input type="checkbox"/> 4) 1 & 2                       |                                              |

Causality

What do you think causes this kind of minor illness?

- exposure
- over-tired
- virus, germs
- situational
- diet
- other: \_\_\_\_\_

How does your child explain illness in him or herself?

- |                                                   |                                       |
|---------------------------------------------------|---------------------------------------|
| <input type="checkbox"/> germs                    | <input type="checkbox"/> too weak     |
| <input type="checkbox"/> no explanation           | <input type="checkbox"/> don't know   |
| <input type="checkbox"/> punishment for being bad | <input type="checkbox"/> other: _____ |

Compliance

How well do you think you follow medical advice from your doctor:

- for yourself \_\_\_\_\_
- for your child \_\_\_\_\_

Health-Maintaining Behaviors

Our family engages in the following activities:

- regular medical check-ups
- regular dental check-ups
- regular immunizations

Our family emphasizes the importance of:

- a) adequate sleep, b) good nutrition, c) regular exercise (please list appropriate letters)
- |                                       |                                      |                                                 |
|---------------------------------------|--------------------------------------|-------------------------------------------------|
| <input type="checkbox"/> for children | <input type="checkbox"/> for parents | <input type="checkbox"/> for all family members |
|---------------------------------------|--------------------------------------|-------------------------------------------------|

19.

To what extent do you engage in exercise as a family? \_\_\_\_\_

To what extent do you engage in exercise as individuals? \_\_\_\_\_

\_\_\_\_\_

To what extent do your your family is concerned about health issues?

\_\_\_\_\_

Do members of your family try to avoid contact with sick people? \_\_\_\_\_

Do you ever feel your child's illness is a punishment from God? \_\_\_\_\_

What do you think is the best treatment for this kind of minor illness?

\_\_\_\_\_ leave it alone - child will cure him/herself

\_\_\_\_\_ take child to doctor

\_\_\_\_\_ bed rest and liquids

\_\_\_\_\_ antibiotic course

\_\_\_\_\_ other: \_\_\_\_\_

20.

PAST EXPERIENCE WITH ILLNESS

Do you feel that your family has had more than \_\_\_\_\_; less than \_\_\_\_\_;  
the same amount \_\_\_\_\_, of illness as other families?

When you were growing up, which of the following statements would most  
accurately describe your family's attitude toward illness:

\_\_\_\_\_ my family did not pay too much attention to sickness.

\_\_\_\_\_ my family was overprotective of sick members.

\_\_\_\_\_ my family tried to pretend physical illness didn't exist.

\_\_\_\_\_ other: \_\_\_\_\_

## STRESSES OF ILLNESS

Rank order the extent to which the following suffer when your child is sick:

- \_\_\_\_\_ time for self
- \_\_\_\_\_ time with spouse
- \_\_\_\_\_ time with other siblings
- \_\_\_\_\_ work
- \_\_\_\_\_ social activities
- \_\_\_\_\_ exercise

Please rank order the following in terms of inconvenience during child's sickness:

- \_\_\_\_\_ additional housekeeping chores
- \_\_\_\_\_ sleepless nights
- \_\_\_\_\_ additional expenses
- \_\_\_\_\_ lifestyle interfered with
- \_\_\_\_\_ work interfered with
- \_\_\_\_\_ coordinating healthcare
- \_\_\_\_\_ logistical problems