

Questionnaire on Family Financial Burden of Child with Acute Lymphoblastic Leukemia

A、 Family Background Information

1. Your date of birth (solar calendar): _____. You are the child's (a) father (b) mother.
2. Your place of residence (province): _____, your current HuKou location: _____, your current Hukou status: (a) rural (b) urban
3. Date of birth of your spouse (solar calendar): _____, your spouse's place of residence (province): _____, your spouse's current Hukou location: _____, your spouse's current Hukou status: (a) rural (b) urban
4. Place of residence of your child (province): _____, your child's current Hukou location: _____, your child's current Hukou status: (a) rural (b) urban
5. Does your child live with his or her parents? (a) Yes (b) No
6. Prior to the child illness, your child's education level was :(a) not in school (b) in kindergarten (c) in primary school (d) in junior high school
7. Prior to the child illness, your family had a total of ____ people, including____ people with income. After the child fell ill, did your family have new-born child? (a) Yes (b) No
8. Your education level: (a) no formal education (illiterate) (b) primary school or below (c) junior high school or below (d) the high school/technical school (e) college/university (f) master degree or above
9. Education level of your spouse: (a) no formal education (illiterate) (b) primary school or below (c) junior high school or below (d) the high school/technical school (e) college/university (f) master degree or above
10. Prior to the child illness, your average monthly income was _____RMB, your spouse's average monthly income was _____RMB, and your family's average

annual income was _____RMB.

11. Did you own your current residence prior to the child illness? (a) Yes (b) No
12. Did your family belong to low income family prior to the child illness? (a) Yes (b) No
13. Did you purchase social medical insurance for your child before his/her illness?
(a) Yes (b) No
If yes, the insurance purchased was: (a) Urban Resident Basic Medical Insurance
(b) Children's Hospitalization Fund (c) New Rural Cooperative Medical Insurance (d) others
If no, after the child fell ill, did you child enroll in social medical insurance? The enrolled social medical treatment insurance was _____(fill one list in Q13).
14. Did you receive medical assistance for your child after the child became ill?
(a) Yes (b) No
15. Did you purchase commercial health insurance for your child before the child became ill? (a) Yes (b) No
If yes, how many commercial health insurances you purchased for your child:
(a)1 (b)2 (c) more than 2

B、 Family Financial Burden

B.1 Direct Medical Costs

1. The date of your child's diagnosis at the Children's Medical Center was _____,
The completion date of the first three-phase treatment in the Children's Medical Center was _____
2. During the first three-phase treatment, the total medical costs paid to the Children's Medical Center were _____ RMB, to other medical institutions were _____RMB, including:
 - (a) medical insurance paid: _____ RMB, among them, the commercial medical insurance paid: _____ RMB.
 - (b) medical assistance (including funded by the Children's Medical

Center): _____ RMB.

3. During the first three-phase treatment, the costs that your family paid for purchasing the medicines from other medical institutions were about _____ RMB.

B.2 Direct Non-medical Costs

4. During the treatment, your family's average monthly costs on food were _____ RMB. Compared with the costs before child's illness, the increased average monthly costs on food were _____ RMB.

5. Did your family purchase large electronic products (such as computer, video games, television, refrigerator, etc.) for your child during his or her treatment?
(a) Yes (b) No

If yes, the costs were _____ RMB. Among them, computer: _____ RMB, video games: _____ RMB, television: _____ RMB, refrigerators: _____ RMB, others: _____ RMB.

6. Did your family buy toys for your child during the treatment? (a) Yes (b) No

If yes, the costs were _____ RMB. Compared with the costs before child illness, the new toy purchase expenses were _____ RMB.

7. Your family spent an average of _____ RMB on communications per month during the child's treatment. The increased average monthly communication fee was _____ RMB, compared with fee before child illness. If you registered for online service for your child, the total costs of the Internet were _____ RMB.

8. During the treatment of child, your average monthly costs on purchasing hygiene cleaning products and related materials were _____ RMB. The costs of purchasing auxiliary treatment facilities (e.g., ultraviolet disinfection lamp, air purifier, humidifier, etc.) were _____ RMB.

[If you do not live in Shanghai, please answer question 9. If you live in Shanghai, please answer question 10.]

9. If you do not live in Shanghai, what kind of transportation did you and your family usually take to and from the Children's Medical Center during your child's

treatment? (a) train (b) coach (c) plane (d) others _____

You and your family traveled to Children's Medical Center altogether ___ times.

The average costs per person on transportation were _____RMB. The total costs of transportation were_____RMB.

10. If you live in Shanghai, what kind of transportation did you and your family usually take to and from the Children's Medical Center during your child's treatment? (a) taxi (b) family car (c) others

On average, you and your family commuted from home to Children's Medical Center ___ times each month. Every time the transportation costs were_____RMB. The total costs of transportation were _____RMB. (If using family car, please estimate the costs of fuel, tolls and parking fees, *etc.*)

11. Did you rent an apartment near the hospital for the convenience of your family during your child's hospitalization? (a) Yes (b) No.

If yes, the agency fee was _____RMB. The average monthly rent was _____RMB. The average monthly payment for utility was _____RMB. You rent for a total of _____ months.

12. Did you hire a day laborer while your child was hospitalized? (a) Yes (b) No

If yes, you total hired_____ months. Day laborer worked_____ hours a day; hour salary was _____RMB; day laborer worked _____days per month.

B.3 Indirect Costs

13. Before the child fell ill, what was the type of your work unit: (a) government agency (b) State-owned enterprises (including state-owned holding enterprises) (c) Private enterprise (d) Overseas-invested enterprises, foreign-funded enterprises or foreign-invested enterprises (e) public institution (f) Individual household or freelancer (g) farmer (h) Unemployed

[If question 13 you chose (a)-(e), please answer question 14; If (f)-(h), please answer question 15.]

14. What change did your employment situation have during your child's treatment?

(a) unchanged (b) discontinuation of work (c) short-term leave (d) long-term leave (including irregular leave) (e) others_____

If (c), the average monthly salary or work income decreased by_____%.

If (d), the length of absence from work was_____months. The average monthly salary or work income decreased by_____%

15. What change did your employment situation have during your child's treatment?

(a) unchanged (b) discontinuation of work (c) reduction of workload (d) others__

If (b), you stop working altogether _____months, the average yearly income decreased by_____%.

If (c), due to the reduction of workload, the average yearly income decreased by_____%.

16. Before the child fell ill, what was the type of your spouse work unit: (a)

government agency (b) State-owned enterprises (including state-owned holding enterprises) (c) Private enterprise (d) Overseas-invested enterprises,

foreign-funded enterprises or foreign-invested enterprises (e) public institution (f)

Individual household or freelancer (g) farmer (h) Unemployed

[If question 16 you chose (a)-(e), please answer question 17. If (f)-(h), please answer question 18.]

17. What change did your spouse's employment situation have during your child's treatment? (a) unchanged (b) discontinuation of work (c) short-term leave (d) long-term leave (including irregular leave) (e) others

If (c), the average monthly salary or work income decreased by_____%.

If (d), the length of absence from work was_____months. The average monthly salary or work income decreased by_____%

18. What change did your spouse's employment situation have during your child's treatment?

(a) unchanged (b) discontinuation of work (c) reduction of workload (d) others

If (b), your spouse stop working altogether _____months, the average yearly income decreased by _____%.

If (c), due to the reduction of workload, the average yearly income decreased by _____%_

19. During the first three-phase treatment, was there other relative besides you and your spouse caring for the child? (a) Yes (b) No

If yes, _____(who) cared for the child, he or she cared for ____ months. His or her work unit was _____ (no work, please fill “no”). The average monthly income loss for caring child was _____RMB.

20. During the first three-phase treatment, did you hire a full-time staff besides your family to accompany your child? (a) Yes (b) No.

If yes, she or he escorted for a total of _____ months, earning _____RMB.

21. During the first three-phase treatment, other large non-medical expenses that your family incurred for your child included _____. The average expenditure increased _____RMB per month.

B.4 Other Information

1. (Just ask parents with rural Hukou) Before you decided to go to Children’s Medical Center for treatment, were you and your spouse aware of the new policy announced by the National Ministry of Health in early 2011 concerning that children's leukemia would be reimbursed by the new rural cooperative medical system (NCMS) for 70%, and the Serious Disease Relief Fund would give 20% compensation according to the family situation? (a) Yes (b) No
2. In terms of medical expenses, reimbursement and concern and other aspects for children’s leukemia, do you have any suggestions or appeals to hospital, Health Administrative Department, Medical Insurance Department and other relevant government departments?

3. If we still have questions regarding the questions in the questionnaire, or we want to know more about your family's financial burden and pressure in the future, can

we contact you directly for further inquiry? (1) Yes (2) No

Your mobile phone number: _____ Signature of parents: _____

The researcher's comprehensive evaluation of the quality of this questionnaire is:

(1) high (2) medium (3) low

Signature of interviewer: _____

Date of signature : _____