

# Survey on Quality of Life and Educational Status of Children with Malignant Tumors

Dear Fellow Patients, To gain an understanding of the real quality of life and educational status of children with malignant tumors aged 0-18, and to enhance the social visibility and social support for this group, we sincerely invite family members of children with malignant tumors to complete the following questionnaire. It will take approximately 10-15 minutes.

The information you provide will be used exclusively for academic research purposes and will comply with national laws, policies, and research ethics. Later in the questionnaire, we will ask for your contact information, which will only be used for questionnaire quality control and follow-up interviews (if needed) and will never be disclosed to third parties. Thank you for your contribution to supporting the malignant tumor patient community!

## I. Basic Information of the Patient

1. Are you a family member of a minor with a malignant tumor? 【Single Choice】  
  
☐ Yes  
  
☐ No (Please skip to the end of the questionnaire and submit)
2. What is the patient's age? 【Fill in the blank】

3. What is the patient's household registration type? **【Single Choice】**
- ☐ Agricultural household registration
  - ☐ Urban household registration
4. Does the patient have the following types of insurance? **【Multiple Choice】**
- ☐ Basic medical insurance for urban and rural residents
  - ☐ New Rural Cooperative Medical Scheme (NCMS)
  - ☐ Public medical insurance
  - ☐ Inclusive commercial supplementary medical insurance / Commercial health insurance
  - ☐ Others
  - ☐ No insurance
5. Permanent residence of the patient's family before illness **【Dropdown Single Choice】**
- ☐ Anhui ☐ Beijing ☐ Chongqing ☐ Fujian ☐ Gansu ☐ Guangdong ☐ Guangxi ☐ Guizhou ☐ Hainan ☐ Hebei ☐ Henan ☐ Heilongjiang ☐ Hubei ☐ Hunan ☐ Jilin ☐ Jiangsu ☐ Jiangxi ☐ Liaoning ☐ Inner Mongolia ☐ Ningxia ☐ Qinghai ☐ Shandong ☐ Shanxi ☐ Shaanxi ☐ Shanghai ☐ Sichuan ☐ Tianjin ☐ Tibet ☐ Xinjiang ☐ Yunnan ☐ Zhejiang ☐ Hong Kong ☐ Macao
6. Location of longest medical treatment **【Dropdown Single Choice】**
- ☐ Anhui ☐ Beijing ☐ Chongqing ☐ Fujian ☐ Gansu ☐ Guangdong ☐

Guangxi ☐ Guizhou ☐ Hainan ☐ Hebei ☐ Henan ☐ Heilongjiang ☐ Hubei  
☐ Hunan ☐ Jilin ☐ Jiangsu ☐ Jiangxi ☐ Liaoning ☐ Inner Mongolia ☐  
Ningxia ☐ Qinghai ☐ Shandong ☐ Shanxi ☐ Shaanxi ☐ Shanghai ☐  
Sichuan ☐ Tianjin ☐ Tibet ☐ Xinjiang ☐ Yunnan ☐ Zhejiang ☐ Hong Kong  
☐ Macao

7. During the entire treatment process, has the patient received treatment in another location for more than one month? **【Single Choice】**

- ☐ Yes - Cross-provincial medical treatment
- ☐ Yes - Intra-provincial medical treatment in another location
- ☐ No

8. Duration of medical treatment in another location (fill in a number, unit: months) **【Fill in the blank】** **【Only required if Option 1 or 2 is selected in the previous question】**

\*Note: You may stay in the treatment location for observation for a period after treatment ends. Here, please fill in the time when you left the treatment location (i.e., when you ended the rental). If you are still receiving medical treatment in another location, please fill in "2022".

9. After treatment ends, do you plan to stay in the treatment location?

**【Single Choice】** **【Only required if Option 1 or 2 is selected in the previous question】**

- ☐ Yes

- ☐ No - Return to hometown
- ☐ No - Move to another city

## II. Patient's Diagnosis and Treatment Status

1. What disease does the patient have? 【Single Choice】

- ☐ Leukemia - Acute Lymphoblastic Leukemia (ALL)
- ☐ Leukemia - Acute Myeloid Leukemia (AML, formerly "Acute Non-Lymphocytic Leukemia")
- ☐ Leukemia - Chronic Lymphocytic Leukemia (CLL)
- ☐ Leukemia - Chronic Myeloid Leukemia (CML)
- ☐ Lymphoma - Hodgkin Lymphoma (HL)
- ☐ Lymphoma - Non-Hodgkin Lymphoma (NHL)
- ☐ Solid Tumor - Glioma
- ☐ Solid Tumor - Medulloblastoma
- ☐ Solid Tumor - Astrocytoma
- ☐ Solid Tumor - Craniopharyngioma
- ☐ Solid Tumor - Ependymoma
- ☐ Solid Tumor - Neuroblastoma
- ☐ Solid Tumor - Hepatoblastoma
- ☐ Solid Tumor - Nephroblastoma (Wilms Tumor)
- ☐ Solid Tumor - Osteosarcoma
- ☐ Solid Tumor - Ewing Sarcoma

- ☐ Solid Tumor - Rhabdomyosarcoma
- ☐ Solid Tumor - Retinoblastoma
- ☐ Solid Tumor - Germ Cell Tumor
- ☐ Others 【Fill in the blank: \_\_\_\_\_】

2. What treatment methods has the patient received? 【Multiple Choice】

\*

- ☐ Chemotherapy
- ☐ Radiotherapy
- ☐ Bone marrow or organ transplantation
- ☐ Surgery
- ☐ Targeted therapy
- ☐ Immunotherapy
- ☐ Others \_\_\_\_\_\*

3. Which stage of treatment is the patient currently in? 【Single Choice】 \*

- ☐ Under treatment - First round of treatment
- ☐ Under treatment - Relapse
- ☐ Post-treatment - Recovery period
- ☐ Post-treatment - Returned to normal life

4. In which year was the patient diagnosed? 【Fill in the blank】

5. In which year did the patient complete treatment? 【Fill in the blank】

【Only required if Option 3 or 4 is selected in "Which stage of treatment is the patient currently in?"】

6. Is the patient currently hospitalized? 【Single Choice】 \*

☐ Yes

☐ No

7. Total length of hospital stay since the patient's diagnosis? 【Single Choice】 \*

☐ Never hospitalized since diagnosis

☐ Less than 1 year

☐ 1 year

☐ 2 years

☐ 3 years

☐ 4 years

☐ 5 years

☐ More than 5 years

### III. Basic Information of the Patient's Family

1. Who are the main caregivers of the patient? 【Multiple Choice】

☐ Patient's mother

☐ Patient's father

☐ Patient's paternal grandfather

☐ Patient's paternal grandmother

☐ Patient's maternal grandfather

☐ Patient's maternal grandmother

- ☐ Patient's elder brother
- ☐ Patient's elder sister
- ☐ Nurse/Aide
- ☐ Others: **【Fill in the blank: \_\_\_\_\_】**

2. What is your relationship with the patient? **【Single Choice】**

- ☐ Patient's mother
- ☐ Patient's father
- ☐ Patient's paternal grandfather
- ☐ Patient's paternal grandmother
- ☐ Patient's maternal grandfather
- ☐ Patient's maternal grandmother
- ☐ Patient's elder brother
- ☐ Patient's elder sister
- ☐ Other relationship **【Fill in the blank: \_\_\_\_\_】**

3. What is your gender? **【Single Choice】** **【Only required if "Other relationship" is selected in the previous question】**

- ☐ Male
- ☐ Female

4. What is your age? **【Single Choice】**

- ☐ 20-30 years old
- ☐ 31-40 years old
- ☐ 41-50 years old

☐ 51-60 years old

☐ Over 61 years old

5. What is your educational background? **【Single Choice】**

☐ Primary school or below

☐ Junior high school

☐ Senior high school or technical secondary school

☐ Bachelor's degree or college diploma

☐ Master's degree or above

6. What was the patient's father's occupation before diagnosis? **【Single Choice】**

☐ Management in Party and government organs, public institutions, and social organizations

☐ Enterprise managers

☐ Private enterprise owners

☐ Medical staff

☐ Professional and technical personnel

☐ Staff in Party and government organs and public institutions

☐ Individual business owners

☐ Commercial service personnel

☐ Industrial workers

☐ Agricultural workers

☐ Unemployed



- ☐ Out of work
- ☐ Underemployed
- ☐ Unclear

7. What was the patient's mother's occupation before diagnosis? 【Single Choice】

- ☐ Management in Party and government organs, public institutions, and social organizations
- ☐ Enterprise managers
- ☐ Private enterprise owners
- ☐ Medical staff
- ☐ Professional and technical personnel
- ☐ Staff in Party and government organs and public institutions
- ☐ Individual business owners
- ☐ Commercial service personnel
- ☐ Industrial workers
- ☐ Agricultural workers
- ☐ Unemployed
- ☐ Out of work
- ☐ Underemployed
- ☐ Unclear

8. What is the patient's father's current occupation? 【Single Choice】

- ☐ Management in Party and government organs, public institutions,

and social organizations

- ☐ Enterprise managers
- ☐ Private enterprise owners
- ☐ Medical staff
- ☐ Professional and technical personnel
- ☐ Staff in Party and government organs and public institutions
- ☐ Individual business owners
- ☐ Commercial service personnel
- ☐ Industrial workers
- ☐ Agricultural workers
- ☐ Unemployed
- ☐ Out of work
- ☐ Underemployed
- ☐ Unclear

9. What is the patient's mother's current occupation? 【Single Choice】

- ☐ Management in Party and government organs, public institutions, and social organizations
- ☐ Enterprise managers
- ☐ Private enterprise owners
- ☐ Medical staff
- ☐ Professional and technical personnel
- ☐ Staff in Party and government organs and public institutions

- ☐ Individual business owners
- ☐ Commercial service personnel
- ☐ Industrial workers
- ☐ Agricultural workers
- ☐ Unemployed
- ☐ Out of work
- ☐ Underemployed
- ☐ Unclear

10. What is the marital status of the patient's parents? **【Single Choice】**

- ☐ Unmarried
- ☐ Married
- ☐ Divorced (including remarriage of one or both parties)
- ☐ Widowed
- ☐ Unclear

#### **IV. Family Financial Burden**

1. What are the main sources of funds for treatment and living expenses?

**【Multiple Choice】**

- ☐ Salary (including performance bonuses, incentives, etc.)
- ☐ Profits from running a store, company, or selling agricultural products
- ☐ Property and investment appreciation (rent income, bank interest,

investment and financial management returns, etc.)

- Gifts and support from parents, children, relatives, and friends
- Government subsidies (pensions, unemployment subsidies, subsidies for the "Five Guarantees" households, subsistence allowances, low-income marginal subsidies, etc.)
- Fundraising through commercial platforms (Shuidichou, Qingsongchou, Wuyouchou, and other commercial fundraising platforms)
- Charitable assistance (relief funds from public welfare organizations; individual fundraising on public welfare platforms such as Tencent Public Welfare, Alipay Public Welfare, etc.)

2. What is your current annual household income? (Unit: 10,000 RMB)

**【Fill in the blank】**

\*Annual household income refers to the total income of all family members (including grandparents if the child lives with them and shares income and expenses) from salaries, bonuses, subsidies, agricultural production, profits from individual businesses or private enterprises, various government subsidies and relief funds, income from renting or selling property, deposit interest, and investment in financial products, minus taxes and social insurance premiums (endowment insurance, medical insurance, unemployment insurance,

work-related injury insurance, maternity insurance) and housing provident fund.

3. What was your annual household income before the patient became ill? (Unit: 10,000 RMB) **【Fill in the blank】**

\*Annual household income refers to the total income of all family members (including grandparents if the child lives with them and shares income and expenses) from salaries, bonuses, subsidies, agricultural production, profits from individual businesses or private enterprises, various government subsidies and relief funds, income from renting or selling property, deposit interest, and investment in financial products, minus taxes and social insurance premiums (endowment insurance, medical insurance, unemployment insurance, work-related injury insurance, maternity insurance) and housing provident fund.

4. What is your current family debt situation? **【Single Choice】**

- ☐ No debt
- ☐ Below 100,000 RMB
- ☐ 110,000 - 200,000 RMB
- ☐ 210,000 - 300,000 RMB
- ☐ 310,000 - 400,000 RMB
- ☐ 410,000 - 500,000 RMB
- ☐ 500,000 - 1,000,000 RMB

☐ 1,000,000 - 2,000,000 RMB

☐ 2,000,000 - 3,000,000 RMB

☐ Above 3,000,000 RMB

5. As of now, what is the cumulative out-of-pocket medical expenditure (after medical insurance reimbursement) during the patient's treatment? (Unit: 10,000 RMB) **【Fill in the blank】** **【Only required if Option 1 or 2 is selected in "Treatment Status"】**

Total medical expenditure includes registration fees, hospitalization fees, treatment fees, medication fees, etc. It does not include rent, transportation, or lost wages.

Please only answer the amount you need to pay out of your own pocket after medical insurance reimbursement.

6. What is the total out-of-pocket medical expenditure (after medical insurance reimbursement) during the patient's treatment? (Unit: 10,000 RMB) **【Fill in the blank】** **【Only required if Option 3 or 4 is selected in "Treatment Status"】**

Total medical expenditure includes registration fees, hospitalization fees, treatment fees, medication fees, etc. It does not include rent, transportation, or lost wages.

Please only answer the amount you need to pay out of your own pocket after medical insurance reimbursement.

7. After diagnosis, what is your family's annual transportation cost?

**【Single Choice】**

- ☐ 0 - 500 RMB
- ☐ 501 - 1,000 RMB
- ☐ 1,001 - 1,500 RMB
- ☐ 1,501 - 2,000 RMB
- ☐ 2,001 - 2,500 RMB
- ☐ 2,501 - 3,000 RMB
- ☐ 3,001 - 3,500 RMB
- ☐ 3,501 - 4,000 RMB
- ☐ 4,001 - 4,500 RMB
- ☐ 4,501 - 5,000 RMB
- ☐ Above 5,000 RMB

8. Did you choose to rent a house to facilitate caring for the patient?

**【Single Choice】**

- ☐ Yes
- ☐ No

9. What is the monthly rental cost (including rent, water, electricity, and internet)? **【Single Choice】** **【Only required if Option 1 is selected in the previous question】**

- ☐ 0 - 1,000 RMB
- ☐ 1,001 - 2,000 RMB

- ☐ 2,001 - 3,000 RMB
- ☐ 2,001 - 3,000 RMB
- ☐ 3,001 - 4,000 RMB
- ☐ 4,001 - 5,000 RMB
- ☐ 5,001 - 6,000 RMB
- ☐ 7,001 - 8,000 RMB
- ☐ 8,001 - 9,000 RMB
- ☐ 9,001 - 10,000 RMB
- ☐ Above 10,000 RMB

10. How many months have you been renting a house so far? **【Fill in the blank】** **【Only required if Option 1 is selected in the question before last】**

## **V. Patient's Educational Status**

1. Has the patient reached school age? **【Single Choice】**
  - ☐ Yes
  - ☐ No
2. What is the patient's current status of in-school education? **【Single Choice】** **【Only required if Option 1 is selected in the previous question】**
  - ☐ Never attended school
  - ☐ Consistent with ordinary students (attending school all day, or



having online classes due to the epidemic)

- ☐ Attends school but has issues with absences or leave
- ☐ Suspended from school (school status retained)
- ☐ Dropped out of school
- ☐ Others \_\_\_\_\_

3. From diagnosis to now, for how many months has the patient's basic in-school education been interrupted? (Unit: months) **【Fill in the blank】** \* **【Only required if Option 2, 3, 4, 5, or 6 is selected in the previous question】**

1 year = 12 months. If there is no interruption, please fill in "0".

4. Did the patient ever study in another location due to treatment?

**【Single Choice】** **【Only required if Option 1 or 2 is selected in "During the entire treatment process, has the patient ever received medical treatment in another location?" and the patient has reached school age】**

\*Studying in another location refers to attending primary school, junior high school, senior high school, etc., in the location where the patient receives medical treatment.

- ☐ Yes
- ☐ No

5. During treatment, what are the sources of education the patient receives? **【Multiple Choice】**

- ☐ School education
- ☐ Paid education (e.g., private tutoring, cram schools, paid online courses, etc.)
- ☐ Open online resources (e.g., social media, open online courses, etc.)
- ☐ Public welfare services (e.g., Xinyangguang Ward School, volunteer tutoring, etc.)
- ☐ Parental tutoring
- ☐ Self-study by the patient
- ☐ Others **【Fill in the blank】**
- ☐ None of the above educational forms

6. During treatment, what are the contents of the courses the patient receives? **【Multiple Choice】** **【Only required if any option except the last one is selected in the previous question】**

- ☐ Basic subjects (e.g., Chinese, Mathematics, English, Science, etc.)
- ☐ Artistic hobbies (piano, vocal music, painting, handcrafts, etc.)
- ☐ Sports hobbies
- ☐ Health education (e.g., basic disease popularization, life education, sex education, etc.)
- ☐ Psychological education (psychological adjustment, mindfulness meditation, etc.)
- ☐ General education (literacy, object recognition, basic life skills, social

rules and etiquette, etc.)

☐ Others \_\_\_\_\_\*

7. During treatment, how many hours does the patient study on average per day? 【Single Choice】

☐  $\leq 1$  hour

☐ 2 hours

☐ 3 hours

☐ 4 hours

☐ 5 hours

☐ 6 hours

☐ 7 hours

☐ 8 hours and above

8. In your opinion, what aspects of courses does the patient need to receive during treatment? 【Matrix Question】

- Basic subjects (e.g., Chinese Language Arts, Mathematics, English, Science, etc.)
- Artistic hobbies (e.g., piano, vocal music, painting, handcrafts, etc.)
- Sports hobbies
- Health education (e.g., basic disease popularization, life education, sex education, etc.)

- Psychological education (e.g., psychological adjustment, mindfulness meditation, etc.)
- General education (e.g., literacy, object recognition, basic life skills, social rules and etiquette, etc.)

[Very Necessary / Necessary / Hard to Say / Unnecessary / Very Unnecessary]

## **VI. Patient's Physical, Psychological, and Social Functions**

1. Does the patient have any of the following types of disabilities?

【Single Choice】

- No disability
- Physical disability
- Intellectual disability
- Mental disability
- Visual disability
- Hearing disability
- Speech disability
- Multiple disabilities

2. Please evaluate the patient's physical, psychological, and social functions. 【Single Choice】

### 【Physical Dimension】

- The patient can walk easily for more than 10 minutes
- The patient can keep up with other peers when participating in sports or exercise
- Compared with before diagnosis, the patient has a more regular sleep schedule and better sleep quality
- Compared with before diagnosis, the patient shows signs of tiredness more frequently

### 【Emotional Dimension】

- Compared with before diagnosis, the patient shows signs of anxiety more frequently (Reverse-scored)
- Compared with before diagnosis, the patient shows signs of fear more frequently (Reverse-scored)
- Compared with before diagnosis, the patient shows signs of sadness more frequently (Reverse-scored)
- Compared with before diagnosis, the patient shows signs of anger more frequently (Reverse-scored)

### 【Personality Dimension】

- The patient's personality has changed significantly before and after falling ill

- The patient's current mental state is more sensitive than that of peers
- Compared with before diagnosis, the patient has become more introverted
- The patient is more mentally mature than peers

#### 【Social Function Dimension】

- Compared with before diagnosis, the patient's language expression ability has declined (Reverse-scored)
- Compared with before diagnosis, the patient's social skills have declined (Reverse-scored)
- Compared with before diagnosis, the patient has fewer friends (Reverse-scored)
- Compared with before diagnosis, the patient faces more mockery and isolation (Reverse-scored)

#### 【Disease Cognition Dimension】

- The patient fully understands their physical condition
- The patient often discusses their physical condition and treatment with family and friends
- You have found that the patient deliberately hides physical discomfort (Reverse-scored)

- Compared with before diagnosis, the patient is more cautious and pays special attention to what their body can and cannot do (Reverse-scored)

### 【Family Relationship Dimension】

- Compared with before diagnosis, the patient has a closer relationship with family members
- Compared with before diagnosis, the patient communicates more with family members
- Compared with before diagnosis, the patient expresses feelings of guilt to family members more frequently (Reverse-scored)

### 3. What are the patient's main daily activities? 【Ranking Question】

\*(Rank 1 as the activity the patient spends the most time on/considers most important, 2 as the next, ..., 8 as the least important). 【Unlimited number of options】

\*Only rank the activities the patient actually engages in; no need to rank those not done.

- ☐ Studying
- ☐ Reading extracurricular books
- ☐ Chatting online
- ☐ Playing video games
- ☐ Watching short videos

- ☐ Offline socializing (playing with peers offline, playing with toys)
- ☐ Playing with toys alone
- ☐ Developing hobbies (e.g., singing, dancing, painting, musical instrument performance)

4. What is the patient's social circle like during treatment?

- During treatment, about \_\_\_ people from the patient's original social circle continue to keep in touch with the patient.
- During treatment, about \_\_\_ people from the patient's original social circle live in the same city as the patient during treatment.
- During treatment, the patient has made \_\_\_\_\_ new friends, among whom \_\_\_\_\_ are fellow patients.
- During treatment, the patient has \_\_\_\_\_ friends with whom they can interact offline, among whom \_\_\_ are fellow patients.

## VII. Summary

For family members, what is the priority of care at this stage? 【Ranking Question】 \*

\*Please rank the following options in the brackets in order of importance, with 1 being the most important, 2 the next, and 5 the least important.

[ ] The child's physical condition

[ ] The child's mental health



☐ The child's educational status

☐ The child's social needs

☐ The child's extracurricular hobbies

Before the child was diagnosed, how would you rank the importance of the following options? **【Ranking Question】**

☐ The child's physical condition

☐ The child's mental health

☐ The child's educational status

☐ The child's social needs

☐ The child's extracurricular hobbies

What is your biggest expectation for your child now? **【Fill in the blank】**

What are your thoughts on the child's education? **【Fill in the blank】**

Please invite your child to answer the following questions. **【Optional】**

- If I could say one sentence to other sick children, I would say: \_\_\_\_\_
- If I could change one thing about the treatment process, what I would most hope for is: \_\_\_\_\_

- If I hadn't gotten sick, the thing I would most want to do now is:

\_\_\_\_\_

WeChat ID

Mobile Phone Number

Are you willing to accept a follow-up interview? **【Single Choice】**

- Yes
- No